

Title:

**Understanding the Dignity Experience and Exploring
the Impact of Dignity Therapy and Guided Imagery on
Patients with Advanced Disease - a South African
Perspective**

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***“One’s dignity can be assaulted, vandalized and cruelly mocked, but it can never
be taken away unless it is surrendered.” Michael J Fox***

***“If a man happens to find himself, he has a mansion
he can inhabit with dignity all the days of his life.” James A. Michener***

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I have appreciated how the spirit is so remarkable! Even in turmoil, when everything is crumbling around you, there can be such resilience and power...the fighting spirit that rises above the circumstances. I appreciated the grave impact of bodily illness on the dignity of someone who has everything, and yet the astounding resilience of one who has a serious bodily illness and whose social structures absolutely cannot support them. On the other hand, I met a determined young woman who was able to convert a Stage IV cancer with excellent support, a fighting spirit and purpose. When one takes the time to understand the self and appreciate one's intrinsic worth, and accepts one's disease, be it AIDS or cancer, one can live with pride as a master when every bone is crumbling, literally! In our unique SA context, we need to understand that it is not easy to speak about dignity when the basic needs are not met and when there are so many social evils that suffocate those in poverty. Support is a very important aspect of dignity! Yet the willpower of the soul can turn nothing into everything. Even if there is rejection, if one has purpose, in who they are, what they have to do, they can conquer.

Having the opportunity to share has lightened the burden and lifted the spirits. Even for one who has nothing (or feels he/she has nothing), when one is able to share and hear one's worth, one has hope. Everyone needs support and understanding. God is also such a strength, such a support for these individuals. Current day thinking can make one quite self-centred, chasing after tangible pursuits of happiness, yet these souls with nothing tangible to hold onto have the biggest hearts... they have taught me boundlessly in how they gently impact the world. These interviews inspire me to be a better person. I want to live, I want to share, I want to love.

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Abstract

Objectives: This study was conducted to understand the dignity experience of patients with advanced disease from diverse socio-economic and cultural backgrounds in a South African context. In addition, the psychotherapeutic interventions, Dignity Therapy and Guided Imagery (focused on intrinsic dignity), were implemented to enhance the dignity experience of these patients and its impact explored.

Method: This was a qualitative study where a semi-structured interview guide was used in the exploration of the understanding of the dignity experience of patients with advanced diseases, receiving home care from two hospices in the North of Durban, KwaZulu-Natal. Interviews were audiotaped and transcribed verbatim. Data was analysed using thematic analysis. Dignity Therapy and Guided Imagery were subsequently implemented with these patients. Dignity therapy is an appreciative enquiry into the lives of patients to allow them to discuss aspects of their life that matter most, and the legacy and words of advice they would want most remembered. The sessions are audiotaped, transcribed and edited to produce a legacy document that can be given to their family or loved ones, if they so wish. Guided Imagery was implemented to affirm a practical experience of patients' intrinsic dignity and worth as beings. A post intervention patient feedback questionnaire, which involved a quantitative and qualitative component, was used to explore the impact of these interventions on different aspects of psychosocial and existential distress. The qualitative feedback was analysed using content analysis to determine the themes and sub-themes of benefit derived from the bundled interventions.

Results: Four major themes defined the dignity experience: physical concerns, psychological concerns and coping mechanisms, social concerns and spiritual concerns and coping mechanisms. These themes and the numerous sub-themes provide an understanding of the total dignity experience of South African patients living with advanced disease. This study provided quantitative and qualitative data illustrating the impact of Dignity Therapy and Guided imagery, which proved to enhance the dignity experience of patients with advanced disease. The beneficial impact of Dignity Therapy and Guided Imagery on the dignity experience of dying patients was documented with confirmations on measures of helpfulness (100%), satisfaction (100%), a heightened sense of dignity (75%), purpose (100%) and meaning in life (92%). Further endorsements

were expressed in terms of 83% sharing that it had lessened their sense of suffering, and feelings of anxiety and depression (92%) and improved their will to live (83%). The participants also expressed that the beneficial impact of interventions would spread beyond themselves to help their families (92%) and to benefit their relationship with their healthcare providers (92%). The interventions were shown qualitatively to have a beneficial impact on the Physical, Psychological, Social and Spiritual Domains of the participants' lives and these emerged as the four themes with various sub-themes.

Conclusion: With this awareness of the biopsychosocial and existential concerns and psycho-existential coping mechanisms that affect the total dignity experience, healthcare providers can optimise dignity conserving care to improve the quality of lives of patients living with advanced disease. In this small study, Dignity Therapy and Guided Imagery are shown to be relevant, feasible and acceptable, short psychotherapeutic interventions that can be conducted at the bedside by healthcare providers to enhance the dignity experience of patients. A Guided Imagery focused on intrinsic dignity is shown to be a novel beneficial 5-minute intervention that can augment Dignity Therapy, or be used on its own, to affirm and strengthen the experience of the intrinsic worth of patients with advanced disease. Healthcare professionals have an influence in the area of the extrinsic sources of dignity in advanced disease, and can enhance dignity in providing respectful compassionate care. To add to the knowledge on dignity research, this study specifically highlights the need to affirm intrinsic dignity in dying patients, to affirm their personal worth.

1. Introduction

1.1 Palliative Care and Respect for the Individual

“Palliative Care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (1) The goal of palliative care is improving quality of life. Quality of life relates to a patient’s subjective experience of satisfaction with life, and this changes as a patient’s experience and expectations change (2). The emphasis is on care that is patient-centred, which begins with open, honest and clear communication and sharing of information so that the patient understands his illness, how it will affect him and possible options for care. With good understanding, the patient can participate in mutual decision making, in terms of goals of care and management options. Thus, respect for the individual patient and his illness experience is central to palliative care.

1.2 Holistic Care

Care that optimises the quality of life of patients encompasses holistic or total care that includes the physical, psychological, social and spiritual (existential) domains of life. Several studies propose that the predominant distressing problems in the life of an individual with life-threatening illness are psychosocial and existential (3-5). In order to provide total patient-centred care that improves the quality of life and provides relief from suffering of patients with life-threatening illness, these very significant issues need to be understood and managed (6-8). Relief of these distressing psychological and existential symptoms often provides concomitant relief of the physical symptoms, many of which have been exacerbated by undiagnosed and unmanaged psychological and spiritual distress. Empirical studies into the psychosocial needs of patients during physical illness has been on the increase for the last two decades (6,9,10). However, systemically developed and well-studied interventions that cater for these psychosocial and existential needs still lag behind interventions that cater for the physical needs of patients (11,12).

1.3 Dignity – at the Heart of Palliative Care

Dignity is a core value in palliative care. A basic principle of palliative care is to help the patient live and die with dignity, in conjunction with symptom control, and psychosocial and spiritual well-being in order to achieve the goals of optimizing quality of life (13,14).

Dignity is defined as “a quality or state of being worthy, honored, or esteemed”, according to Webster’s International Dictionary (15). The word dignity is derived from the Latin word, dignitas, meaning worthy. Over time, the concept of dignity has encompassed completely opposite poles – from an aristocratic position of status through to a thoroughly democratic position of universality.

Kant (16) wrote: “But man regarded as a person...that is, as the subject of a morally practical reason...possesses a dignity (an absolute inner worth) by which he extracts respect for himself from all other rational beings in the world.” According to Kant, human dignity was founded in the human capacity for free moral choice and is intrinsic or innate, yet it is also conditional and dependent on self-determination.

Following the formation of the United Nations, there was a major focus on the concept of dignity. Human rights initiatives state that dignity is intrinsic to all human beings, whether or not an individual possesses rational autonomy (17). Dignity is absolute, inherent and not dependent upon self-governance. All people, including the young, intellectually disabled and cognitively impaired are born free and equal in dignity and rights. Dignity is present because you are human - a truly universal sense of intrinsic dignity belonging to every human being. Possessing reason and conscience, all human beings should thus act towards one another in a spirit of brotherhood (17,18)

1.4 Intrinsic and Extrinsic Dignity

As stated by Brennan (19), dignity is seen as innate, inherent, universal and intrinsic to being human, and all human beings have this attribute and nothing, not even serious illness, can remove it. It is present and absolute, an objective concept referred to as intrinsic dignity. Sulmasy (20) describes intrinsic dignity as the worth and value that

human beings have simply because they are living human beings, “not by virtue of any set of biological, psychological, social, economic, or political conditions, nor of the views of other persons, nor of any particular set of talents, skills, or powers.” It is the value of the living spirit that is equal in all human beings and uninfluenced by human choices or circumstances. Whilst dignity as a subjective attribute, that is how a person views him or herself or how they are viewed by others, is referred to as extrinsic or attributed dignity. Extrinsic dignity is situational. In serious illness, the loss of independence and control and how one is treated by others, and the associated physical and emotional suffering may be viewed as a loss of dignity.

Brennan describes that a person may possess an intrinsic dignity but endure indignities and the gap between the two may be defined as suffering. With dignity conserving care, the goal is that the “loss of attributed dignity does not rob a person of intrinsic human dignity”, and that every person is both worthy and worthy of our concern (19). Chochinov’s Dignity Conserving Care describes approaching a person with compassion and respect, to maintain and enhance an individual’s attributed dignity (21).

1.5 Challenges to Dignity Resulting from Illness

The WHO definition of palliative care includes the principle that, “Palliative care affirms life and regards dying as a normal process, integrates the psychological and spiritual aspects of patient care and will enhance the quality of life and positively influence the course of illness.” (1) The progression of serious illness often results in physical and personal insults that may damage a person’s sense of attributed dignity. Patients with advancing disease may struggle to live with dignity and accept death as a normal phase of life with the intensifying biological, psychological, social, and spiritual challenges they may experience (3-5). As the body fails and the mind is challenged with the burden of unfinished business, their self-worth may be threatened. Proulx (22) found that “death is a unique experience for each human being”, and whilst dignity is “an intrinsic, unconditional quality of human worth”, it is affected by “the external qualities of physical comfort, autonomy, meaningfulness, usefulness, preparedness, and interpersonal connection.” In Proulx’s concept analysis, patients described dying as a “process, rather

than a moment in time”, and its experience is determined by a favourable balance of scientific technology and the transcendence of spirituality. As disease advances, achieving this balance in patient care is the challenge for the palliative care physician.

1.6 Dignity Poorly Understood

The term dignity amongst the dying is used widely but is poorly understood. In recent times, it has gained widespread popularity in end-of-life discussions, but is still poorly understood even in this context. The understanding of dignity in these debates are not empirically based nor from the viewpoints of dying patients themselves. An understanding of dignity from the dying themselves (10,23-25) will help us appreciate the increasing fears of loss of dignity resulting in lobbying for legalizing of assisted death (5,26-28). It will also help health care workers in optimizing compassionate holistic care for the dying, promoting dignity in living and in dying a natural death. It is unfortunate that ‘death with dignity’ has become commonly associated with physician assisted suicide and euthanasia, “removing it from its place as a principle of bedside care for patients nearing death.” (21)

The International Association for Hospice and Palliative care (IAHPC), in its position statement on physician assisted suicide and euthanasia (29), states that no country or state should consider legalization of euthanasia unless there is universal access to palliative care and adequate access to essential medication such as opiates for pain and dyspnea. The term ‘death with dignity’ is discussed as death after adequate bedside palliative care in terminally ill patients, not as commonly used to describe physician assisted suicide and euthanasia. Failure to provide access to palliative care violates the state’s duty to respect, protect and “fulfil the right to health and to prohibit cruel, inhumane and degrading treatment” (30,31). With the provision of palliative care, basic effective inexpensive medical and nonmedical strategies applied at home are successful in alleviating the suffering and loss of control associated with dying for the majority of patients. Patients who lack access to pain relief are at increased risk for suicide and wish for hastened death (32). Palliative care supports attentive respectful listening of patients wishing for hastened death. It is found on discussion of this wish, that only rarely is it a

request to act (29). Acknowledging this wish, physicians should interpret this as a starting point to begin to understand their patients better and to provide better holistic care. For many patients, it is the anticipated fears and suffering, the fear of loss of control and being a burden to family that trigger a wish to die. These fears need to be heard and discussed with the patient with the aim to offer appropriate psychosocial and spiritual care. Healthcare systems should respond to such needs of dying patients by providing caregivers and motivating societies to create compassionate community networks (33-35) that provide care for these vulnerable citizens. The concern is that if people only accord others dignity when they are 'intact', then the risk is a decision to extinguish the life 'not worth living', thus undervaluing the elderly, sick and physically and mentally disabled. Physician assisted suicide and euthanasia are in direct conflict with the WHO definition of palliative care not to hasten nor postpone natural death, and professional ethical codes like the Hippocratic Oath (36) to provide care and preserve life. Legalization would erode the physician-patient relationship and would violate this bond of trust, undermining the integrity of a profession dedicated to safeguard human life.

Patients with advanced illness, if given the chance, assign their own unique understanding to the concept of dying with dignity, inclusive of "practical matters such as basic comfort, the tone or quality of care, and considerations of the soul or spirit." (21) A comprehensive understanding of the meaning and importance of dignity from the perspective of a patient at the end of life provides a framework that can guide clinicians and families in providing the best care in this vulnerable phase of life.

1.7 Empirical Research to Understand Dignity

In an effort to understand the dignity experience from a patients' perspective, Chochinov and colleagues have conducted a number of studies to understand the factors that may support or undermine the dignity of an individual with a life-threatening illness, and consequently developed a dignity model (10). According to this model, difficult illness-related concerns and challenging social circumstances are seen to have a damaging effect on dignity. A positive dignity conserving approach comprises dignity conserving perspectives and practices which may buffer the experience of these negative influences.

This empirically derived model of dignity for patients with life-threatening illness offers a theoretical framework that provides a foundation to assist health providers and family understand how a patient with advanced disease may experience a diminishing of their dignity. It also offers direction for the construction of dignity-enhancing interventions to support patients nearing end-of-life. Based on the dignity model, the dignity interventions - Dignity Psychotherapy (37) and Dignity Conserving Care (38) - were generated by Chochinov et al to enhance dignity in patients with advanced disease.

1.8 Dignity Psychotherapy

Dignity psychotherapy is a brief individualized psychotherapeutic intervention developed by Chochinov et al to support patients with psychosocial and existential distress who experience a waning of their dignity. This is a brief bedside psychotherapeutic intervention that borrows elements from supportive therapy, logotherapy, existential psychotherapy, life review and life narrative, and has been shown to enhance the dignity of patients with advanced disease and also support their loved ones (37).

1.9 Dignity Conserving Care

“To feel sick is one thing, but to feel that *who we are* is being threatened or undermined—that we are no longer the person we once were—can cause despair affecting body, mind, and soul.”(38). From the dignity model, it is noted that the care provided by healthcare providers and how healthcare providers view people seeking their care has an influence on the experience of being a patient. “How patients perceive themselves to be seen” is an influential moderator of their dignity (39,40). For patients with terminal cancer, perceptions of damage to dignity were most powerfully related to “feeling a burden to others” (41-44) and “sense of being treated with respect.”(45) Therefore, to uphold a patient’s sense of dignity, health care providers are encouraged to affirm the individual patient’s value by seeing each individual as the person that they are, as opposed to just the illness they are seeking care for. This resonates with Sir William Osler famous words – “it is much more important to know what sort of patient has a disease than what sort of disease a patient has”. Patients are human beings with a life story, not just the illness

they have in the present moment in time. The basis of Dignity Conserving Care is founded on this close connection between the healthcare provider's affirmation of the patient and the patient's self-perception (21). Chochinov describes that health care practitioners should attend to Attitude, Behaviour, provide Compassionate care and effective Dialogue with patients in order to provide Dignity Conserving Care (38).

However, many healthcare providers are reluctant to support this domain of care, which is categorised as psychosocial care or spiritual care which is considered beyond their scope of clinical care (37,46-48) The reasons given are lack of expertise or time required to support this. However, if patients are not affirmed for the person they are, they are more likely to feel that they are not being treated with respect and dignity (42), which can damage their sense of worth (39). Patients who feel that they no longer have worth, or meaning and purpose in life are more likely to feel that they are a burden to others. They may then start to question the meaning of their continued existence (43,49,50). Healthcare delivery has become disconnected from the basic values of kindness and compassion, and this requires as Peabody stated that "treatment of disease takes its proper place in the larger problem of the care of the patient." (50)

1.10 The Physician's Challenge

The physician's challenge in caring for the dying patient is to understand how each individual patient and family uniquely experiences dignity and to create interventions that enhance their dignity and feelings of worth. Healthcare providers of end-of-life care can feel inadequate and demoralized without adequate strategies or interventions to address suffering (51). Sulmasy (52) said that "to treat oneself or others with less than the proper esteem is to behave in an undignified manner." Thus, the practice of dignity conserving care protects the dignity and wellbeing of the patient, family and the provider equally. As Chochinov said, "Dignity-conserving care comprises not only what one does to patients, but how one views patients. When dying patients are seen, and know that they are seen, as being worthy of honor and esteem by those who care for them, dignity is more likely to be maintained. In turn, caregivers are imbued with the dignity rendered by their actions, better enabling them to provide care and comfort to those nearing death." (21)

1.11 How to Affirm Intrinsic Dignity

The Institute of Medicine has defined quality end-of-life care to be determined by the key domains of overall quality of life and achieving a sense of spiritual peace and well-being. Equally, “a sense of spiritual peace, relieving burden, and strengthening relationships with loved ones” are considered by patients to be the most important aspects of end-of-life care (53). The role of palliative care is to treat and support patients in all challenges that reduce their attributed dignity and overshadow their intrinsic dignity. Therapies are aimed to restore the dignity of the patient and to help re-establish meaning and value in the patient’s life. However according to its definition intrinsic dignity is innate, imperishable and beyond the assaults on their attributed dignity. “The difficulty lies with those whose attributed dignity has been so damaged that they believe that their own intrinsic dignity has been vanquished: that they truly have no worth, that their personhood has been forever fractured” (19).

Brennan uses the expression, “Mrs. Smith – this disease has done many things to you. And it will continue to do so. But it can never take away who you are – your spirit. That is untouchable.” (19) Intrinsic dignity is inherent and yet it falters, because the lived experience of this highly abstract and complex concept of one’s innate dignity is lacking. Thus, having an experience of the “untouchable spirit” and one’s innate intrinsic dignity and self-worth can bolster total dignity in patients with terminal illness. Intrinsic dignity cannot simply be a philosophy but requires an applied experience for conviction.

1.12 The Use of Guided Imagery to Aid an Experience of Intrinsic Dignity

Experience is a powerful motivator. Intrinsic dignity is not a theoretical concept. It is an unconditional state of the being that is worthy, honoured and esteemed. This intangible abstract concept needs to be felt and practiced to create an indelible experience that builds conviction of one’s intrinsic worth. South African people value story-telling and experiential learning as an oral tradition of learning. Dignity cannot be taught but needs a practical experience to be caught by the individual. Thus, in this study in conjunction with Dignity Therapy, we explore the use of Guided Imagery to facilitate the learning and

experience of innate dignity, to aid in affirming the intrinsic dignity of patients. Guided Imagery consists of various techniques of relaxation which concentrate the mind on positive images in an attempt to reduce pain and stress. It includes simple visualization and direct suggestion using imagery, story-telling, game playing, drawing etc. Once considered an “alternative” or “complementary” approach, guided imagery is now being used to teach psychophysiological relaxation, alleviate anxiety and depression, relieve physical and psychological symptoms, overcome health-endangering habits, resolve conflicts, and help patients prepare for surgery and tolerate procedures more comfortably.

Using the definition of intrinsic dignity as innate, inherent, untouchable and choosing words in alignment with the themes found in research that support dignity conserving care, a Guided Imagery has been created for this study that aims to support an experience of the intrinsic dignity of the being that is worthy of respect and esteem. We hope to affirm the intrinsic dignity of the spirit in patients, a dignity that is unconditional beyond the assaults of people and circumstances, through the addition of this experiential method of Guided Imagery to the Dignity Therapy Protocol. This will constitute a novel brief psychotherapeutic intervention that will augment Dignity Therapy for enhancing the dignity experience of patients.

1.13 The South African Context

Palliative care is an emerging field in South Africa. In South Africa, some medical educational institutions provide training for undergraduates in palliative medicine and the University of Cape Town offers a post graduate training programme in Palliative Medicine. Patient-centred supportive care to enhance dignity is advocated in the general training of healthcare professionals, but there is no ongoing education and training. Neither is there emphasis on supporting the psychosocial and existential distress that may impact on a dying patients’ dignity in the overburdened government sector hospitals of South Africa (54,55). In the non-governmental sector, hospices in South Africa offer palliative care which supports patients diagnosed with life-threatening illness to live and die with dignity by providing holistic compassionate care that includes methods to address psychosocial distress.

In 2012, approximately 608 000 people in South Africa died of which 43% of deaths were reported as being due to Non-Communicable Diseases. Yet only about 90 000 people accessed palliative care through hospices in South Africa, so how did the other 260 000 die?¹

No studies have been conducted to understand the personal dignity experience of the culturally diverse South African population during illness. There are no formalized local dignity enhancing interventions that have been practiced and implemented with regards to improving the dignity experience of South African patients with advanced illness. There are no studies in South Africa on dignity enhancing interventions and its impact on the total care and experience of the patient with a life-threatening illness. Yet, it is indeed a privilege of palliative care practitioners to support a patient at this crucial part of their journey as best as we can, with best available empirical methods. Observing the need to understand the dignity experience of dying South African patients and the need for supportive psychotherapeutic interventions at this crucial time, the researcher valued the beneficial impact of dignity therapy evidenced in international studies on mitigating psycho-existential distress. Further noting that accepting one's intrinsic dignity is quintessential to uplifting total dignity, the researcher added the experiential tool of Guided Imagery to Dignity Therapy to deliver an experience of intrinsic worth. This topic was chosen by the researcher to investigate empiric methods to support dying South African patients.

1.14 Summary

To meet the goals of palliative care, and to provide holistic patient-centred compassionate care that respects the experience of patients with advanced disease, the experience of dignity in its entirety needs to be understood from the patients' perspective. This understanding will support the healthcare provider to offer dignity conserving care. Whilst dignity is accepted as an unconditional inherent worth possessed by all living beings,

¹ http://www.who.int/nmh/countries/zaf_en.pdf?ua=1, Accessed on 6 December 2017

there is a labile extrinsic component that is based on how patients view themselves and how they are viewed by others. If the experience of the intrinsic and extrinsic dignity of individuals can be strengthened, this can improve the total experience of dignity in the dying. There are no studies to understand the predominant factors that impinge on the dignity experience of South Africans, nor any formal dignity enhancing interventions that are being practiced in South Africa. There is a need to understand the dignity experience of South Africans from diverse socioeconomic and cultural backgrounds and to explore the impact of dignity enhancing interventions that strengthen both intrinsic and extrinsic dignity. We use a novel intervention of Guided Imagery in addition to Dignity Therapy to affirm the experience of intrinsic and extrinsic dignity respectively in this study.

2. Literature Review:

A literature search was conducted on medical, psychology and sociology electronic databases: Medline, Scopus, EBSCOhost, ScienceDirect, PsycARTICLES, PsycInfo, Google Scholar and Socindex. Key words used were: “Dignity”, “Dignity in Palliative Care”, “Dignity in the Dying”, “Dignity End of Life Care”, “Human Rights and Dignity Africa”, “Dignity Community South Africa”, “Dignity Therapy”, “Chochinov”, “Learning Styles in South Africa”, “Experiential Learning”, “Guided Imagery”. Communication also occurred with Prof. H. Chochinov, who also referred the researcher to the following sites: www.dignityincare.ca, www.virtualhospice.ca

The literature review starts with an exploration of previous studies on the understanding of dignity in the end-of-life, and then goes on to expound the Dignity Model as developed from patients’ perspectives on dignity. We then explore initial studies conducted on Dignity Psychotherapy, followed by studies conducted internationally to assess its feasibility and benefits. Thereafter other psychotherapeutic interventions used to support patients in the end-of-life are analysed. This is followed by an exploration of dignity in the unique South African context, South African learning styles and empiric evidence of the benefits of Guided Imagery.

2.1 Studies to Understand Dignity Among Patients with Advanced Disease

Focusing on symptom control, level of functioning and negative events that may compromise dignity, Turner *et al.* (56) attempted to measure dignity in fifty patients under the care of a busy integrated palliative care facility during the last three days of their life. This study illustrated difficulties in describing and assessing the notion of dying with dignity. A limitation of the study was that it relied solely on the healthcare provider’s assessment of dignity. A better understanding of this concept is needed from a qualitative enquiry into the perspectives of patients with life-threatening illness. A concept analysis of articles on dignity by Gamlin (57) explored the views of patients, relatives and health care providers who described “dignity as dynamic and changeable”. An exploration of its meaning included respect, control and choice. However, the depth of exploration that can be achieved by qualitative studies could not be met by an online search of articles.

Pokorny (58) and Soderberg *et al.* (59) explored experiences of dignity in intensive care using qualitative methods. Soderberg's study of 85 case studies related by 20 registered nurses showed that, "Dignity had a positive, transforming effect but demanded attentiveness, awareness, personal responsibility, engagement, fraternity and defence." (59) However, this once again was an understanding of dignity from the healthcare provider's perspective. In Pokorny's study amongst patients, dignity meant privacy, control and independence (42). The study also revealed a link between the dignity of a patient and the care and competence of the nurse. However, the study did not show the impact of advancing illness on the experience of dignity and it was difficult to define adequate care as it is relative to a patient's experience.

Street and Kissane's (60) case studies of dying patients and family members illustrate how they feel about their bodies and the care they receive. It illustrated that a source of shame and revulsion for the patient with terminal illness might be abjection of the body i.e. the subjective horror that a patient experience when confronted with one's physical reality. It is a process whereby one separates their sense of self from that which they consider intolerable and infringes upon their 'self' i.e. the object. This serves as a reminder that patients' perceptions of their worth are significantly influenced by how care providers care for and communicate with them.

Enes (44) explored in depth the meaning and experiences of dignity for patients (in the last few months of life) and providers of palliative care. Dignity was described as a complex phenomenon. It comprises of the dimensions of "being human", "having control", "relationship and belonging" and "maintaining the individual self", all of which may change with advancing symptom distress in illness and treatment administered to cope. Clinical care to support dignity was found to be challenging because "it involves balancing the multiple needs of both users and providers of palliative care and the different perceptions and dimensions of dignity itself." (44)

Proulx (22) in her concept analysis of 26 articles on dying with dignity from 1985 to 2002 using the matrix method, found that the core view of dying with dignity is based on the unconditional human worth that acknowledges each one's identity and honours the being of each person. It is born from spirituality and is illustrated by the ability to give and receive

the essential elements of love and compassion in the process of dying. However, the external sources of dignity such as privacy, control, autonomy, freedom from pain, access to spiritual resources, connection with loved ones and preparation for death may enhance or diminish a person's intrinsic sense of dignity. Healthcare professionals have the greatest influence in the area of these extrinsic sources of dignity. Proulx stated that open, honest communication in the therapeutic relationship between healthcare professionals, patients, and their families is essential in honouring the dignity of the dying. "Listening for what matters to each individual patient while planning a way to create meaning and purpose in each person's last days is fundamental to preserving dying with dignity." (22)

In a systematic review of dignity, Leget (61) found that the concept of dignity is vague because there are three versions of dignity that are often confused: subjective dignity, social and relational dignity and intrinsic dignity. These need to be clearly distinguished in order to avoid confusion because all three of them are only partially effective. They may however sustain each other and help achieve what neither one of the versions can do on its own.

In an integrative review article of dignity in end of life care by Guo (62), the themes that emerged were: human rights, autonomy and independence, relief of symptom distress, respect, being human and being self, meaningful relationships, dignified treatment and care, existential satisfaction, privacy, and calm environment. Factors influencing dignity include demographic, illness-related and treatment-/care-related factors and communication. Interventions to support dignity stressed physical, psychological and spiritual supports, not only to dying patients but also to family members.

Rodrigues et al (63) conducted a systematic review to explore the relationship between perceived dignity, autonomy and sense of control in patients at the end of life. Three themes emerged: a) dignity mediated by the loss of functionality and control; b) dignity as identity; and c) autonomy understood as the desire for self-determination and control over the dying process. Whilst dignity and autonomy are intertwined and close to the notion of personal identity, the ability to regard dignity as an intrinsic quality has a positive impact on patients, and thus interventions should take this into account.

2.2 The Dignity Model

In 2002, Chochinov et al (10) conducted studies to determine how patients with terminal illness understand and define the term dignity. Fifty palliative care Australian and Canadian patients were interviewed using semi-structured interviews to gain an understanding of the dignity experience of patients with advanced disease. The content of the interviews formed the basis of a model of dignity comprising of three principal categories that emerged from the qualitative analysis. These categories consist of wide-ranging concerns that dying patients experience as an assault to their sense of dignity in the progression of their illness. Numerous systematically well-defined themes and sub-themes make up these categories which serve as a basis for a model to understand dignity amongst the dying.

Three principal categories:

1. 'Illness Related Concerns' are matters that stem from the illness that impact or threaten to impact the experience of dignity of the patient. In this category, two broad themes are "level of independence" (cognitive acuity and functional capacity) and "symptom distress" (physical distress and psychological distress – medical uncertainty and death anxiety)
2. 'Dignity Conserving Repertoire' consists of two major themes: Dignity Conserving Perspectives and Dignity Conserving Practices. Dignity Conserving Perspectives are understandings held by patients internally of how they view circumstances in the world to maintain their dignity, and consists of role preservation, continuity of self, hopefulness, maintenance of pride, autonomy, resilience, generativity, and acceptance. Dignity Conserving Practices refer to personal attitudes or methods that patients use to reinforce or preserve their sense of dignity and consists of seeking spiritual comfort, maintaining normalcy and living in the moment.
3. 'Social Dignity Inventory' refers to interactions with others (or external sources or issues) that enhance or diminish one's sense of dignity i.e. care tenor, social support, aftermath concerns, privacy boundaries and burden to others.

The dignity model encompasses general effects on dignity but each individual's experience of dignity will be very variable, unique and circumstantial. The study

emphasized that considering the many assaults on a person's dignity as identified by this model, conserving dignity should be customary in the care of all patients nearing death. Thus, this model proposes an approach to understanding how patients experience advancing life threatening disease and serves to promote dignity and quality of life for patients near the end-of-life. Understanding the varied sources of suffering infringing on a patient's dignity as illustrated by the dignity model, multiple interventions can be initiated to support the dying patient to offer total care in end-of-life. This model of dignity offers therapeutic guidance and awareness into how dignity can be preserved or damaged as patients draw closer to death. Each of the themes and sub-themes within the model allude to matters that health providers must be aware of and attend to in order to lessen patient distress and suffering thus promoting dignity conserving palliative care. The model has been validated (45), is supported by factor analysis (64) and is believed to be applicable to any patient population with advanced disease (21).

To further investigate this developing empirical model, Chochinov et al (39) studied a cohort of 213 advanced cancer patients who graded their sense of dignity and completed a battery of psychometric tests to assess symptom distress and mental well-being. This was to determine the impact of demographic and disease-specific variables on the dignity experience of patients. It was found that the patients who expressed that loss of dignity was a significant concern were statistically more likely to express "psychological and symptom distress (increased pain, decreased quality of life, difficulty with bowel functioning), heightened dependency needs (bathing, dressing and incontinence), and loss of will to live, increased desire for death, depression, hopelessness, and anxiety." (39)

In further analysis of the data of the 213 cancer patients above, Hack et al (64) showed that, "there were 99 (46%) patients who reported at least some, or occasional loss of dignity, and 16 (7.5%) patients who indicated that loss of dignity was a significant problem". The exploratory factor analysis produced six main factors: "(1) Pain; (2) Intimate Dependence; (3) Hopelessness/Depression; (4) Informal Support Network; (5) Formal Support Network; and (6) Quality of Life". Ensuing regression analyses of modifiable

factors in this study produced a two-factor model of statistical significance: Hopelessness/Depression and Intimate Dependency. This study provided empirical support for the dignity model, and further suggested that “managing depression, fostering hope, and facilitating functional independence” should be included in the goals of care of the terminally ill.

2.3 Dignity Psychotherapy

The dignity model of care provided the theoretical framework for Dignity Psychotherapy, an original psychotherapeutic intervention to alleviate the distress of patients with terminal illness. Chochinov et al (37) examined this novel intervention that was designed to address psychosocial and existential distress, support a sense of meaning, purpose, and dignity and enhance quality of life for patients with terminal illness. (37,65) The Dignity Model informed the tone, structure and content of the therapeutic intervention. The themes that informed the Dignity Therapy are “generativity,” “role preservation”, “continuity of self,”, “hopefulness”, “maintenance of pride”, “care tenor”, “aftermath concerns.” The therapy involves an interview of 9 questions that delves into the life story of a patient allowing patients the opportunity to create a legacy document that highlights their achievements and accomplishments, moments that were most meaningful or that they were proudest of, things they would want to say or want to take the time to say again, their hopes and dreams for their loved ones and advice they would like to share. It also offers patients an opportunity to address their concerns about what may happen after their death so that they can offer comfort and give instruction to support the soon-to-be bereaved family and friends. Patients are encouraged to reflect on issues that reinforce their sense of self and purpose, meaning and self-worth, thereby decreasing their distress and improving their experience of quality of life. This is recorded, and transcribed verbatim, and reshaped into a narrative after editing the content and ending with an appropriate closing statement. This document is read to the patient and necessary editing is done until the patient is satisfied with it, after which it is handed to the patient as a legacy/generativity document, a concrete product that will survive beyond the patient. This is a personal legacy document that the patient shapes and creates and can bequeath to the family if they wish.

Dignity Therapy was evaluated in a study with 100 terminally ill patients by Chochinov et al (37). The study showed that it was acceptable to hospice patients, feasible to deliver and showed a significant improvement in suffering and depressive symptoms. The majority of participants gave positive evaluations of the benefits experienced from dignity therapy: “91% were satisfied with dignity therapy, 86% reported it was helpful or very helpful, 76% reported a heightened sense of dignity, 68% an increased sense of purpose, 67% a heightened sense of meaning, 47% an increased will to live, and 81% that it had been or would be of help to their family.” (37) The data showed that patients’ experience of finding the psychotherapeutic intervention helpful to their family correlated with a sense of life feeling more meaningful and having a greater sense of purpose, complemented by a lessened sense of suffering and increased will to live.

In a study by McClement et al with the family of deceased patients illustrated that the generativity documents had supported them in their bereavement and would be a source of ongoing comfort (66). Most shared that having benefitted themselves, they would recommend dignity therapy to their families and other patients. Dignity Therapy is unique in that it is a brief psychotherapeutic intervention that has potential benefit for patients with terminal illness and their bereaved families (37,66).

However, a randomized controlled trial (RCT) of Dignity Therapy in 2011 by Chochinov et al found no reduction in distress after dignity therapy. Thus, the ability of dignity therapy to alleviate outright distress such as depression and desire for death or suicidality remains to be proven (67). One possible reason for these conflicting results could be the low baseline levels of distress in the population sample. Nonetheless, patients in the intervention group reported greater benefits from taking part in the study than the control groups on 13 of 22 ratings. Dignity therapy was reported to be significantly more likely than the other two interventions (standard palliative care or client-centered care) to increase a sense of dignity, to have been helpful to patients and family, to improve quality of life and to assist how their family appreciated and saw them. It was significantly better in improving spiritual wellbeing than client-centred care. It was also significantly better in

lessening sadness or depression than standard palliative care and significantly more patients reported that the study group had been satisfactory. It is also noted that both control groups experienced benefits from participating in the study. The impact of Dignity Therapy on largely non-distressed population samples have been difficult to assess thus far (37,67). To aid in explaining these findings, qualitative methods may help.

2.4 Dignity Therapy Studies Internationally

Numerous studies have been conducted to assess the impact of dignity therapy on psychosocial and existential wellbeing internationally. In the United Kingdom, Hall et al (50) used a mixed-methods approach for patients with advanced cancer in a Phase II RCT of Dignity Therapy. There were no differences between the intervention and control group on primary outcomes of dignity-related distress, quality of life and anxiety and depression. Quantitative findings in the intervention group showed higher levels of hope at one and four-week follow-up. Patients stated that it had helped them and that it helped or would help their families. Participation in the study had also helped the control group but to a lesser extent. To understand more deeply how patients and their families were helped, a qualitative study was undertaken by Hall et al (51). In this study, patients and their families found that Dignity Therapy helped them in many ways. However, it was noted that patients in the control group occasionally perceived comparable benefits from partaking in the study. This highlights components of Dignity Therapy that are shared with dignity conserving care.

Houmann et al in a Danish study with ten health care providers and twenty patients showed that with minor cultural adaptations, the dignity therapy intervention created by Chochinov et al was “a manageable, acceptable and relevant intervention for Danish patients admitted to palliative care.” (68) There were issues with recruitment and retention.

Dignity Therapy was also found in a pilot study in rural Kentucky with eight patients with terminal cancer to be feasible by videophone, and can attain high patient satisfaction and general benefit (69).

In French-speaking Canada, a cohort of 33 patients with advanced disease participated in a study done by Gangnon et al. This study showed that Dignity Therapy was relevant and patients and satisfaction with Dignity Therapy was high for patients and patients' families (70).

In Japan, in a study done by Akechi et al (71) among 22 eligible patients admitted to two palliative care units, 19 patients (86%) refused with only three patients (14%) participating. Whilst at another site eight agreed to take part in the study. Patients reported benefits in improving dignity (67%), meaning in life (56%), purpose (44%), sense of well-being (56%), decreasing suffering (44%), helpfulness for family (78%), and recommendation for other patients (33%). Akechi found that there is a possible influence of cultural differences. Firstly, there is a disparity regarding the understanding of a 'good death' between cultures – this possibly had influenced the lower participation rate. In Japan 'unawareness of death' is a notion of good death according to a previous Japanese study (72). Despite receiving specialised palliative inpatient care, patients who wish to remain "unaware" of their approaching death may less probably participate in dignity therapy for fear of confronting information they did not wish to receive. Secondly, the comparatively higher refusal rate in Japan versus Western countries (67), suggests that Japanese patients with terminal cancer in Japan attempt to cope with their disease by denial. Among cancer patients, whilst denial is a frequently observed mental defense strategy (73), Japanese patients seem more likely to cope with death anxiety using denial (74). Furthermore, Japan has many distinctive cultural differences: their communication style is usually indirect, nonverbal, and there is an unspoken understanding or heart-to-heart communication (75). Japanese people don't put great value on saying goodbye to loved ones etc. in preparation for death but emphasise the value of euphemistic communication (72). Thus, the study suggests that Dignity Therapy may be of benefit for Japanese patients who want to leave a legacy, but should not be recommended to all patients with advanced disease.

However, in another Japanese study of 88 patients by Michiyo et al (76), the psychometric tests for hopefulness, spiritual distress, Life Completion and Preparation Scores, Suffering, Burden and Hospital Anxiety and Depression scales for patients with terminal illness who underwent Short Term Life Review (which included Dignity Therapy) showed significantly greater improvement and greater alleviation of suffering compared to control. Short Term Life Review was thus shown to be effective in improving the spiritual well-being of patients with terminal illness and relieving psychosocial distress and supporting a good death.

In a further study by Juliao et al (77) in Portugal, Dignity Therapy resulted in a significant beneficial effect on depression and anxiety symptoms in end-of-life care with therapeutic benefit sustained over a 30-day period.

A small feasibility study of Dignity Therapy among 15 outpatients receiving second line chemotherapy with Stage IV colorectal cancer was conducted by Vergo and colleagues, with an 88% participation rate (78). Outcomes that were assessed included death acceptance (which was assessed by peaceful awareness and treatment preferences) to assess if Dignity Therapy improves a person's existential maturity (comfort with their mortality). Despite being a small study, the study suggests that Dignity Therapy was acceptable and contributed to better understanding that their illness was likely to result in death and thus less aggressive goals for end-of-life care were agreed. A delayed effect was observed with an escalation in death acceptance from 11% at baseline to 57% at one-month post-intervention.

A mixed method study by Johnston et al (79) demonstrated that Dignity Therapy as a psychosocial intervention is feasible, acceptable and potentially effective to improve the quality of life and enhance person centred care for older people with early stage dementia. Three overarching themes emerged in this study: A life in context; A key to connect; and Personal legacy.

Johnston et al (80), conducted a study to assess the legacy document created by the Dignity Therapy interview and found that it provided knowledge of patients with early stage dementia to inform care and support, as the condition progresses. Main themes from the legacy document were origin of values, essence and affirmation of self, forgiveness and resolution and existentialism/meaning of life. The legacy provides information about the values, self-identity and the people and events that have been important to them and influenced their lives.

In a systematic review of dignity therapy research conducted by Fitchett et al (81), 17 articles representing 12 quantitative studies established that patients who receive DT report high satisfaction and benefits for themselves and their families, including increased sense of meaning and purpose. The effects of Dignity T on physical or emotional symptoms, however, were inconsistent. Three areas for future research were suggested to determine: (1) whether the Dignity Therapy intervention exerts an impact at a spiritual level and/or as a life completion task; (2) how Dignity Therapy should be implemented in real world settings; and (3) if Dignity Therapy has an effect on the illness experience within the context of not only the patient, but also the family and community.

2.5 Other Interventions to Enhance Dignity

Many psychotherapeutic approaches have been considered for end-of-life care. Chochinov et al (82) reviewed these approaches and it was found that for terminally ill patients, supportive therapy has been the pillar of therapy. This includes attenuating anxiety and fear, enhancing adaptive coping mechanisms and minimizing maladaptive mechanisms. Therapeutic approaches that require longer time frames to administer such as insight-oriented therapy or interpersonal therapy are less applicable for patients nearing death.

Realising the need for psychotherapeutic intervention strategies for end-of-life care, a number of researchers began investigating strategies that address suffering, meaning, purpose, will to live, hopelessness and burden to others. “Surface-work” and “depth-work” were described by Kearney and Mount (83) as a response to spiritual pain. Depth-work

are approaches such as image work, dream work, art and music therapy and certain types of meditation that helps an individual reconnect to aspects of life that brought a sense of meaning, albeit simple or ordinary tasks, thus moving the individual toward deeper levels of the consciousness. Surface-work aims to relieve distress experienced by an individual at the conscious level.

In another review by Breitbart of therapeutic interventions for cancer patients at various stages of illness, group psychotherapy is seen to be an effective means of reducing anxiety and depression, psychological distress, physical symptoms and improving quality of life (84). This includes patient education, cognitive-behavioural therapeutic interventions and supportive-expressive interventions that encourage expression of feelings toward illness and changing life circumstances. However, spiritual or existential themes were seldom addressed.

Rousseau (85) suggests practical direction for managing spiritual suffering among patients with advanced disease. This includes: symptom control; a compassionate presence; supporting life review for fostering meaning, purpose and value to life; exploring guilt, regret, forgiveness and reconciliation; enabling religious expression; and promoting healing rather than cure by focusing on meditative practices.

Clarke and Kissane (86,87) also propose demoralization syndrome as an applicable diagnosis in end-of-life care. Demoralization syndrome is defined as “a psychiatric state in which hopelessness, helplessness, meaninglessness, and existential distress are the core phenomena.” (87) The therapeutic approach they recommend includes: active symptom control and ongoing care, exploring attitudes toward meaning in life and hope; promoting hope whilst supporting bereavement; facilitating exploration of rekindled purpose and role; reframing negative beliefs by using cognitive therapy; supporting spiritual aims by involving pastoral counseling; a supportive compassionate environment; inclusion of family meetings; and multidisciplinary team meetings for ongoing review of goals of care.

Some researchers such as Chandler (88) and Robinson (89) suggest that music therapy and art therapy may contribute to the spiritual healing of the dying. Other modalities for spiritual healing include relaxation, aromatherapy, therapeutic touch, guided imagery, biofeedback and acupuncture (88). The efficacy of these therapeutic approaches have been evaluated largely through descriptive and exploratory studies.

Cole and Pargament (90) suggest a psychotherapy program for patients diagnosed with cancer that addresses four existential distresses i.e. identity, meaning, control and relationships by integrating spiritual matters and resources. Whilst focusing on the three main areas of spirit, emotions and relationships, Miller and colleagues (91) have structured a supportive– affective program. Breitbart (92) and Breitbart and Heller (93) are applying the work of Viktor Frankl and his concepts of meaning-based psychotherapy amongst ambulant advanced cancer patients to address existential suffering. This therapy helps patients sustain or augment a sense of meaning and thus peace and purpose in their lives. It can be applied in groups to support groups to make the most of each ones remaining time.

2.6 Understanding of Dignity from a South African Perspective

There is a gap in the body of research knowledge on the understanding of dignity in care from a South African perspective. However, dignity and human rights has been part of the South African discourse amongst different population groups especially in the post-apartheid era and in the drafting of the South African constitution. Dignity is protected in Section 10 of the South African Constitution which states that “Everyone has inherent dignity and the right to have their dignity respected and protected.” Nozizwe Madlala-Routledge founded an NPO called Embrace Dignity² - a women’s human rights organisation in South Africa that seeks dignity for all people. However, there is no research on the dignity experience in illness and dignity in palliative care.

² <http://embracedignity.org.za/embracedignity.org.za/our-team/index.html>, Accessed on 6 December 2017

An article of some relevance to the African context alluding to collectivist versus individualistic conception of dignity was written by Prof Thaddeus Metz, from the University of Johannesburg. In an article on “African conceptions on Human Dignity: Vitality and Community as the Ground of Human Rights” (94), Metz shares that the African conception of human dignity is “what is special about us requiring respect is our capacity for communal or friendly relationships, understood as the combination of sharing a way with others and of caring about their quality of life.” In the West, as per Kant’s conception of dignity, people’s dignity is “constituted by their capacity for rational agency or free will and upholding these rights appears to be naturally understood in terms of respecting individuals’ ability to govern themselves”. In the African conception, “human rights are at bottom ways of respecting people’s capacity for friendly relationships, with human rights violations being roughly a matter of very unfriendly behaviour.” Metz concluded: “I submit that those who believe in human rights as grounded in human dignity have some interesting cross-cultural exploration to undertake.”

Dignity is constituted by our existing relationships with others and by virtue of our capacity for loving relationships. “Umntu Ngumuntu Ngabantu - A person is a person because of others.” **Ubuntu**, is a social philosophy, a way of being, a code of ethics and behavior deeply embedded in African culture and communities that embraces humanity, tolerance and respect. It is a Nguni word that speaks to our interconnectedness, our common humanity and the responsibility to each other (95).

However, a study in the Eastern Cape of South Africa showed that with urbanization and development of overcrowded peri-urban townships, there is an erosion of African communal values due to poverty and lack of resources, crime and substance abuse, lack of trust among community members, impact of foreign cultures and religious beliefs and lack of knowledge and motivation amongst the younger generations (96) . This study amongst students and academics revealed that despite these challenges, family members are still willing to help and support each other. However, the lack of basic physiological and security needs in these peri-urban township areas threatens dignity. As

Maslow stated physiological and security needs precede need for love/belonging, esteem and self-actualisation (97).

2.7 Experiential Learning in South Africa

In *Using Experience for Learning* (98), Postle refers to “the cultural bias in favour of the intellectual and practical”, but states that “emotions and feelings are key pointers to both possibilities and barriers to learning and acknowledging them can enable us to significantly redirect our attention to matters which we have neglected.” He adds, “Denial of feelings is denial of learning.” Thus, in our unique South African context where storytelling and experiential learning is valued in an oral tradition of learning, we add an experiential tool of Guided Imagery to Dignity Therapy to augment learning and experiencing of intrinsic dignity in this study. There are numerous studies that have illustrated the benefits of Relaxation Training and Guided Imagery in improving comfort, decreasing psychological distress and the beneficial impacts on mood, quality of life and even on physical symptoms of pain postoperatively, and nausea and vomiting during chemotherapy (99-103). There is also documented evidence of the beneficial alterations in the immunomodulation of host defences in cancer patients (104). Renz et al (105) in a study of 251 patients with advanced cancer to understand patients’ spiritual experiences, indicated that experience-based spiritual care may complement current needs based approaches.

2.8 Empiric Evidence of the Benefit of Guided Imagery among Cancer Patients

In a RCT of 53 women with Stage I and II breast cancer receiving radiotherapy, Kolcaba et al (99) found that comfort as measured by anxiety levels showed a significant overall increase over time in the group that received Guided Imagery. There was a significant linear trend in differences in comfort levels between the groups.

In a study with 86 cancer patients, Progressive Muscle Relaxation with Guided Imagery showed marked improvement in tests to assess psychological distress and coping with cancer (Impact of Events Scale and Brief Symptom Inventory). Long-term effects showed that for the 58 patients who continued follow-up over the next 6 months, improvement was maintained (100).

In another RCT, of 96 patients with newly diagnosed large or locally advanced breast cancer receiving chemotherapy, those who received Relaxation Training and Guided Imagery were more relaxed and easy going during the study (Mood Rating Scale), had better quality of life (Global Self-assessment and Rotterdam Symptom Checklist) and reduced emotional suppression (Courtauld Emotional Control Scale). Clinical response correlated with ratings of Guided Imagery (101).

Guided Imagery was also shown to lessen preoperative and postoperative anxiety and pain. In a RCT of 130 patients undergoing elective colorectal surgery for cancer, Guided Imagery proved to be a simple, inexpensive tool that can help lessen fear and anxiety among surgical patients, as measured by anxiety levels, pain perceptions, and narcotic medication requirements among these patients. The intervention group required almost 50% less narcotic medications after their surgical procedures than patients in the control group (102).

In RCT of 50 cancer patients receiving intravenous chemotherapy those who received Relaxation Training and Guided Imagery reported feeling significantly less anxious and nauseated during chemotherapy, showed significantly less physiological arousal and less anxiety and depression after chemotherapy, and significantly less severe and protracted nausea at home following chemotherapy. Thus, illustrating the benefit of these interventions on adverse effects of chemotherapy (103).

Eighty women undergoing multimodality treatment for large or locally advanced breast cancers participated in a RCT to evaluate the immuno-modulatory effects of Relaxation Training and Guided Imagery. On 10 occasions during the 37 weeks following the diagnosis, blood was taken for immunological assays CD phenotyping. The intervention beneficially altered putative anti-cancer host defences during and after multimodality therapy, with significant differences in the number of activated T-cells, LAK cells, mature T-cells. Those women who rated their imagery ratings highly had elevated levels of Natural Killer cell activity at the end of chemotherapy and at follow-up (104).

2.9 Summary

Dignity in the end of life, whilst explored in numerous studies in Western Countries, is an essential concept that needs to be explored empirically in South Africa, a country that has a diversity of cultures. Dignity therapy has been explored internationally in Western countries and has been shown to be feasible, acceptable and effective as a psychotherapeutic intervention to support patients with advanced disease suffering from psycho-existential distress. Guided Imagery has also been shown empirically to benefit patients with end stage cancer in Western countries and is a tool that could be considered acceptable in South Africa, a country that seems to favour experiential methods of learning. Thus, this study will explore the notion of dignity and the use of Dignity Therapy and Guided Imagery on the dignity experience of patients with advanced disease in South Africa.

3. Rationale for the Study

In advanced illness, often the greatest challenges for dying patients are psychosocial and existential distress and in this the greatest suffering is experienced when a patient's dignity is fractured. Compassionate care that values the individual patient and their unique experience of illness can enhance dignity. To be able to preserve and support the dignity of the dying, the concept of dignity needs to be explored from the dying patient's experience. Recognising a gap in the South African milieu in the understanding of dignity, this qualitative research will inform the understanding of the dignity experience of patients living with advanced disease from a cross-cultural perspective in the current South African context, thus enabling healthcare providers to offer optimal clinical care to the dying.

Together with treating symptom distress and managing psychosocial distress, dignity enhancing interventions in advanced illness are paramount at this crucial phase of life if we are to enhance the holistic quality of life experience for the dying. There are numerous qualitative and quantitative studies on Dignity Therapy in the developed world that demonstrate the effectiveness of this psychotherapeutic intervention to enhance dignity. There are no studies in South Africa to assess the benefits of dignity enhancing interventions on patients with advanced disease. To enhance intrinsic dignity amongst the sample of South African patients in this study, in addition to Dignity Therapy, Guided Imagery has been implemented with the aim of delivering an experience of the abstract concept of the intrinsic, inherent, innate, untouchable dignity of the patient. The content of the Guided Imagery has been informed by the definition of intrinsic dignity and themes derived from previous research on dignity conserving care. This study will thus implement and explore the impact of a bundled intervention, Dignity Therapy and Guided Imagery (focused on intrinsic dignity), on the total dignity experience of patients with advanced disease, and its relevance and acceptability in a South African context in promoting dignity and quality of life in the dying.

Aim and Objectives

Aim:

To Understand the Dignity Experience and Explore the Impact of Dignity Therapy and Guided Imagery (focused on intrinsic dignity) on Patients with Advanced Disease - from a South African Perspective

Objectives:

1. To explore individual patients' perceived experience of dignity in advanced disease
2. To implement Dignity Therapy and Guided Imagery (focused on intrinsic dignity) for patients with advanced disease
3. To explore the impact of Dignity Therapy and Guided Imagery (focused on intrinsic dignity) on the perceived dignity of patients with advanced disease
4. To explore the relevance and acceptability of Dignity Therapy and Guided Imagery (focused on intrinsic dignity) to enhance the dignity of patients with advanced disease in a South African context

4. Methodology

4. Study Design – This is a descriptive qualitative study. In-depth interviews allow for an exploration of the lived experiences of the participants with advanced disease.

4.1 Study sites – The study sites are Verulam Regional Hospice and Dolphin Coast Hospice in Kwa-Zulu Natal.

4.2 Study Population – Patients with advanced disease enrolled at Verulam Regional Hospice and Dolphin Coast Hospice for home care.

Selection criteria:

Inclusion criteria –

- (1) Patients with advanced disease (Stage III and IV cancer, Stage IV HIV, HIV with co-morbid disease)
- (2) 18 years and older
- (3) English and Zulu speaking patients
- (4) No cognitive impairments, as determined by the Mini-Mental Status Examination

(Appendix 1)

Exclusion criteria –

Patients who were too frail to take part in the study and patients who lack the mental capacity to take part in the study.

4.2.1 Sampling

Purposive sampling was used to identify 14 patients eligible for the study. Recruitment continued to data saturation. To ensure a culturally, linguistically and socioeconomically diverse population that is representative of our South African population, participants receiving palliative care from Verulam Regional and Dolphin Coast Hospice were interviewed.

4.3 Data Collection

4.3.1 Data Collection Tools:

1) Demographics Questionnaire:

A questionnaire (**Appendix 2**) was designed to gather necessary objective demographic information of the research participants – this includes basic demographic information, educational level, occupation, social support structures, diagnosis, length of time from diagnosis and co-morbid illness. Most of this demographic data was obtained from the patients' files.

2) Semi-Structured Interview Guide:

The source Interview Guide consisting of 8 questions (**Appendix 3**) was designed and validated in 2000, by a multi-disciplinary expert panel of clinicians experienced in care of the dying in Canada, and researchers whom were familiar with the literature determined the scope of the interview (10). After discussion with colleagues and my supervisor, the source interview guide was assessed as appropriate for use in our cultural context without changes. This semi-structured interview guide was translated into Zulu for this study and was thus available in two languages (English and Zulu) for the interviewer's use. The interview guide was translated by a professional nurse in the field of family medicine whose first language is Zulu and back translated by a school principal who is fluent in both Zulu and English, to confirm the accuracy of the translation process.

3) A Patient Feedback Questionnaire:

This questionnaire was developed by Chochinov et al in 2001 (37) to evaluate the patients' experience of the Dignity Therapy intervention (**Appendix 4**). The feedback questionnaire takes into consideration the relevant measures of dignity as considered by an expert panel of clinicians in the field of palliative care in Canada such as meaning and purpose, measure of suffering and will to live. It was reviewed, and on discussion with colleagues and supervisor, the questionnaire was found to be suitable for the South African population, with the addition of a question on whether the intervention contributed to a lessened sense of anxiety and depression. This semi-structured interview guide was translated for this study into Zulu and was thus available in two languages (English and

Zulu) for the interviewer's use. The interview guide was translated by a professional nurse who is a first language Zulu speaker in the field of palliative medicine and back translated by a school principal who is fluent in both Zulu and English, to confirm the accuracy of the translation process.

4.3.2 Data Collection Method/Process

The researcher held a seminar with the board and staff of Verulam Regional Hospice and subsequently with Dolphin Coast Hospice staff informing them of the research and of previous research conducted on the topic. The researcher also explained the selection criteria for potential participants and requested hospice staff assistance in recruiting potential participants. Thereafter, the researcher recruited and trained a Zulu speaking assistant from Verulam Regional Hospice in research ethics and the research methodology for this study. The assistant committed to maintaining patient confidentiality. The role of the Zulu speaking assistant was to act as an interpreter only for the researcher. The researcher was present and conducted all interviews but sought the assistance of a Zulu speaking assistant to translate for Zulu speaking patients.

Recruitment of participants:

The Verulam Regional Hospice and Dolphin Coast Hospice staff assisted the researcher with purposive sampling to recruit research participants as per inclusion and exclusion criteria above. A Mini-Mental Status Examination (**Appendix 1**) was conducted by the researcher (with the help of the assistant in the case of Zulu speaking participants) to ascertain mental capacity to participate in the research. If the patient had the cognitive capacity to participate in the study (MMSE > 24), consenting was initiated.

The researcher (with the help of the assistant in the case of Zulu speaking participants) then provided information about the study to each potential participant verbally and each participant was given an information sheet (**Appendix 5**) in their preferred language (English or Zulu). Patients were informed that confidentiality would be maintained throughout the study and that they could withdraw from the study at any time, with no compromise to their quality of care. The participants were given full information of the study and were informed that their participation was completely voluntary and that if they

chose not to take part in the research this would not affect the care or other benefits they received from the hospice. Any queries were addressed to facilitate participant understanding of the research. Once the participant had understood the information surrounding the research and their required participation, the researcher or the trained assistant requested the participants to sign the informed consent forms (**Appendix 6**) in their preferred language (English or Zulu) consenting to the interview and audiotaping of the interview.

Once informed consent had been obtained, a demographics questionnaire (**Appendix 2**) was administered and completed by the researcher. Ensuring privacy and, at a time convenient for the patient and interviewer, the semi-structured interview (**Appendix 3**) was conducted with the participants to assess their dignity experience in advanced disease. The researcher who is trained in qualitative interviewing techniques conducted all interviews. The researcher used the open-ended questions of the interview guide and was led by the participants' responses to explore areas alluded to by the participant that had impacted on their dignity. This allowed the researcher to gather information-rich data unique to each participant's cultural background. Each interview was audiotaped and subsequently transcribed verbatim. In the case of isiZulu speaking participants, verbal translation into English happened simultaneously by the translator from isiZulu to English and the English was transcribed verbatim from the audiotaping. Constant review of the study transcripts allowed the researcher to become familiar with the data and to identify any key issues had been omitted allowing for an iterative process to ensure high quality data was obtained in successive interviews.

At the close of the first interview, the participants were reminded that an intervention which required them to reflect on their life story would form part of the next visit by the researcher and their consent was affirmed. They were provided with the Dignity Therapy Question Protocol (**Appendix 7**) to contemplate on for a day or two. A convenient date was set with the patient within 1-3 days when the Dignity Therapy intervention was to be conducted.

Interventions:

In this study, we explored the impact of a bundled intervention – Dignity Therapy and Guided Imagery on the dignity experience of patients with terminal illness. Using the

Dignity Therapy Question Protocol, an enquiry was made by the researcher into the life, accomplishments, advice and wishes of the participant at the second visit. This interview was firstly transcribed verbatim by the researcher and the participant's dialogue was then captured as a narrative. In the case of isiZulu speaking participants, verbal translation into English happened simultaneously by the translator from isiZulu to English and the English was transcribed verbatim from the audiotaping. For the creation of the narrative by the researcher, the transcripts underwent editing for basic clarifications, chronological corrections, editing of any content that might inflict significant harm or suffering on the transcript's recipients and a statement was found by the researcher within the transcript that provided an appropriate ending to the narrative, as described in the Chochinov protocol (21). This creative process permitted the synthesis of a legacy document. The development of the legacy document was completed by the researcher as soon as possible after the interview in order to present it to the participant, in a timely manner, particularly recognizing the participants' state of health. When the edited narrative was ready, another meeting was set up with the participants at a suitable time to read the document in its totality. After reading the narrative to the participants, they were asked if they wanted to add anything to the legacy document and if there were any errors to be corrected. If there were any additions or errors, the researcher corrected this on the document and another meeting was set with the participant. Their consent was affirmed for another meeting when the corrected legacy document and the Guided Imagery would be read, and a feedback questionnaire administered.

Dignity Therapy will create a springboard for an experience of intrinsic dignity through Guided Imagery. Using the definition of intrinsic dignity as innate, inherent, untouchable and choosing words in alignment with the themes found in research that support dignity conserving care, a Guided Imagery (**Appendix 7**) was created for this study that aims to support an experience of the intrinsic dignity for the patient. Ensuring privacy and at a time that was suitable once again, the final legacy document was read to the participant. This was followed by a reading of the Guided Imagery in a quiet environment with no disturbances. The legacy document was handed to the participant for themselves personally or to be bequeathed to their family if they wished. The Patient Feedback Questionnaire (**Appendix 4**) was administered to the participant to assess the patient's

experience of engaging in Dignity Therapy and Guided Imagery. The feedback was audiotaped to ensure that it would be transcribed verbatim for data analysis.

Distress Protocol:

The research study included a distress protocol which could be used if any participant became distressed during any of the interviews (**See Appendix 9**). In this study, one participant experienced distress but he chose to continue with the intervention as he found that the opportunity to express his distress was therapeutic in itself.

4.3.3 Data Storage and Confidentiality:

The participant demographic data sheet was assigned a code for each participant and all interviews, questionnaires and audiotapes of the participant were assigned the corresponding code to identify the participant. A softcopy Excel datasheet provides information of the codes and corresponding participants and was stored in a separate location under password protection. The hardcopy data and audiotapes relevant to the participant were kept under lock and key in the researcher's office and the Excel datasheet was on the researcher's laptop which is password protected. All research data will be kept for 2 years after publication.

4.4 Data Analysis:

The Chochinov model of dignity was used as the theoretical framework for the study. However, the researcher allowed cultural and socioeconomic differences in South Africa to emerge from the data. The data was analysed using thematic analysis following the steps of familiarisation and immersion in data, inducing themes, coding, elaboration and interpretation, and checking for contradictions or mere summarizing of data, over-interpretation and objectivity in data analysis (77). A process of repeated comparison and review, refining the analysis, resulted in the emergence of the final themes and sub-themes.

1. Data Analysis of Semi-Structured Interview on the Dignity Experience of Patients with Advanced Disease

Whilst conducting the semi-structured interviews and transcribing the audiotaped interviews, patterns of thought and general themes were emerging concurrently. All the interview transcripts from the interviews on the dignity experience of patients were read thoroughly and repeatedly in the process of familiarisation and immersion in the data. This helped build a mental map of the data on the dignity experience of patients in the transcripts, so that the researcher would be able to identify the location of the supporting data in the transcripts when the themes were identified.

Familiarisation with the data allowed induction of the issues in the transcripts. The transcripts were then reread and the issues identified and written in a grid alongside the relevant transcribed data. The major issues consisted of physical concerns and social/community concerns affecting the dignity experience being tempered by psychological and spiritual coping mechanisms to support the dignity experience. Relevant subthemes were also identified under these themes as data analysis developed. The transcriptions were checked several times to ensure that all themes were captured and that no data was missed. The patients' actual words comprised the supporting data to understand the emotive experience of dignity. Themes and sub-themes were reviewed and refined. A process of repeated comparison and review, refining the analysis, resulted in emergence of final themes and subthemes. At each stage, the themes were checked to ensure congruency with the supporting data.

2. Data Analysis of the Quantitative Feedback from the Feedback Questionnaire on the impact of Dignity Therapy and Guided Imagery

After the semi-structure interview, the Dignity Therapy and Guided Imagery were conducted and the feedback questionnaire administered to explore the impact of this intervention. The responses from the feedback questionnaire of the Dignity Therapy and Guided Imagery were also transcribed verbatim. The quantitative results of the feedback were tabulated to explore the impact of Dignity Therapy and Guided Imagery, as expressed by participants.

3. Content Analysis of the Qualitative Feedback from the Feedback Questionnaire on the Impact of Dignity Therapy and Guided Imagery

Patients' qualitative feedback on the benefits were also captured verbatim and were read thoroughly and repeatedly in the process of immersion in the data. This immersion allowed familiarisation with the data so that common ideas and themes started to emerge. A process of repeated review and refining of the analysis resulted in emergence of the themes of the explored benefits of Dignity Therapy and Guided Imagery. Quotes and supporting data were reviewed to ensure they were congruent.

4.5. Ethical Considerations:

The research received ethics approval from the University of Cape Town (UCT) Faculty of Health Sciences (FHS) Human Research Ethics Committee (HREC) and the Hospice Palliative Care Association (HPCA) Research Ethics Committee. Permission from the Directors of the Verulam Regional Hospice and Dolphin Coast Hospice were obtained to conduct research at these institutions. Permission was not granted by the Directors of the first site that was chosen, Highway Hospice, due to lack of staff capacity to assist in recruitment. Despite permission being granted by a second site, Umhlanga Oncology Centre, a private oncology centre, recruitment remained a challenge for the following reasons: most patients that consulted at the practice presented with early disease, a few were critically ill and unable to participate, one had demised and the family members took prolonged periods to consider giving permission. Thus, Dolphin Coast Hospice was approached for permission as a study site. The manager and team of nurses/caregivers agreed to assist with recruitment. Permission was granted by directors of the hospice and the UCT FHS HREC and HPCA research ethics committee approved an amendment of protocol in adding this site. Practical recruitment and informed consenting as detailed above were strictly adhered to for protection of this vulnerable population.

Protection of Vulnerable Populations: This research cannot be carried out in any other population as this research has been specifically designed to understand the dignity experience of patients with advanced disease and to explore the impact of dignity enhancing interventions on patients with advanced disease. The research assistant was

trained by the researcher to ensure that ethical considerations are adhered to. Patients' needs were always considered to be the foremost priority. The chosen participants have terminal illnesses and their physical stamina and emotional state may be fragile and thus a distress protocol was in place (see above) to protect this vulnerable population. The researcher is not a practicing professional at the study site, which limits the likelihood of the participant feeling coerced to take part in the research.

5. Results Chapter

The results of the study are presented in two sections relating to the phases of the study:

- A. Understanding the Dignity Experience of Patients with Advanced Disease, from Semi-Structured Interviews, Qualitative Analysis.
- B. Exploring the impact of Dignity Therapy and Guided Imagery on patients with Advanced Disease, from Feedback Questionnaire
 - 1. Quantitative Feedback from Feedback Questionnaire
 - 2. Qualitative Feedback from Feedback Questionnaire based on responses to enquiry into how the intervention was experienced

Firstly, the demographic data of the twelve patients enrolled at Verulam Regional Hospice and Dolphin Coast Hospice for home care are presented.

5.1 Demographics of Participants

Over a period of seven months, 14 patients were interviewed. Of the 14 patients that were interviewed to understand the dignity experience of those with advanced disease, one patient died after the first interview and so did not complete the study. One other participant had the first interview but was excluded from the study because he was found not to have advanced disease. It was noted that no further new themes were emerging after 12 interviews, at which point data saturation was reached.

The age of the patients ranged from 31 to 84. Seven were male and five were female. Ten had cancer, five had HIV infection and three had HIV infection and cancer. Of the patients with cancer, 6 males had genitourinary cancers (adenocarcinoma of the bladder, transitional cell carcinoma of the bladder, anal cancer and prostate cancer), whilst one male had brain cancer (oligodendroglioma – irresectable) and the 3 females had cancer of the breast, uterine cancer and ovarian dysgerminoma.

Seven were married, one widowed, one separated and three were single. Four of the 12 patients were from a rural township, whilst 8 were from urban areas. The ethnicity comprised of four African, four Indian and four Caucasian patients through purposive sampling. Primary Social Support was either the spouse/children in the case of older patients or family in case of single individuals. For one participant, due to lack of family in

a geographical area, friends or neighbours or the weekly housekeeper were the primary support. Another participant, despite living with and supporting his family financially, had no primary support and was very psychologically distressed about this lack of support. Two participants had to take support from children, because one was widowed and the other was abandoned by her partner after she became ill. Ten participants expressed that they were very spiritual/religious, whilst two shared that they were somewhat spiritual. Except for two Hindus and a Muslim, the rest of the participants were from the Christian faith. Five completed primary school, four secondary school, two tertiary and one post graduate studies. Three were professional, four skilled and five unskilled.

Table 1. Summary of Demographics of Participants (N = 12)		
Variable	Number	Percentage
Gender:		
Male	7	58%
Female	5	42%
Age:		
31-45	4	33%
46-65	3	25%
66-81	5	42%
Diagnosis: Cancer	10	83%
Prostate	3	
Bladder	2	
Anal	1	
Brain	1	
Ovarian	1	
Uterine	1	
Breast	1	
Diagnosis: HIV	5	42%
With Cancer	3	
With Comorbidities	2	
Ethnicity:		
African	4	
Caucasian	4	
Indian	4	

A. Understanding the Dignity Experience of Patients with Advanced Disease from Semi- Structured Interviews

Amongst the 12 patients, many themes and subthemes with respect to the dignity experience of the participants emerged.

Firstly, the themes will be described and secondly the themes will be expressed in the words taken verbatim from participants to further illustrate these themes and subthemes and its impact on the participant's dignity experience.

Four major themes emerged and several sub-themes are expressed within these dominant themes:

1. Physical Concerns
2. Psychological Concerns and Coping Mechanisms
3. Family and Social Concerns
4. Spiritual Concerns and Coping Mechanisms

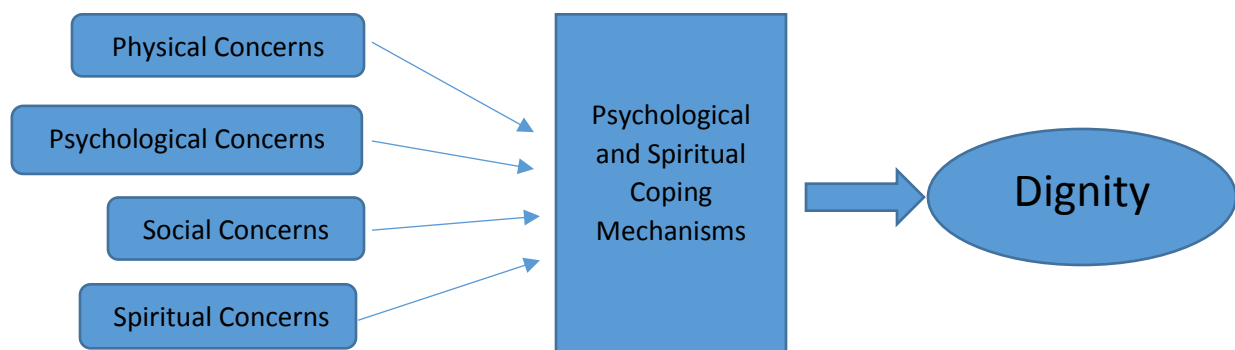
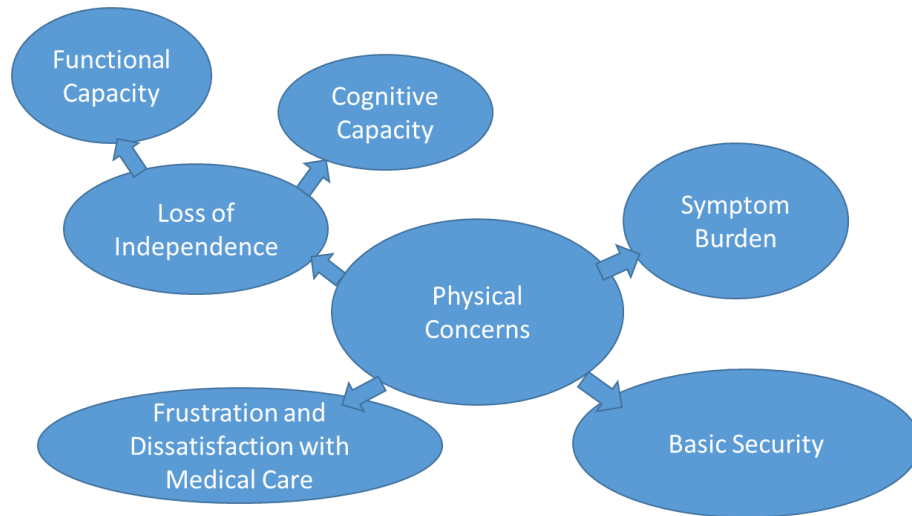


Table 2 Themes and Sub-themes: Dignity Experience of Patients with Advanced Disease

Themes	Physical Concerns	Psychological Concerns and Coping Mechanisms	Family and Social Concerns	Spiritual Concerns and Coping Mechanisms
Sub-themes	Loss of Independence: 1.Functional Capacity 2. Cognitive Capacity	Concerns: Anxiety/Fear Arising from Advancing Disease	Social Support	Concerns: Wanting to Die/Wanting to Live
	Symptom Burden	Resilience/ Overcoming Adversity	Compassionate Care	Support from Personal Spiritual Practices: 1.Affirming Intrinsic Worth 2.Maintaining Hope 3.Acceptance and Letting Go 4.Gratitude
	Frustration and Dissatisfaction with Medical care	Maintaining Autonomy	Respect	Support from Organised Religion and Places of Worship
	Basic Security	Living One Day at a Time	Stigma	
		Leaving a Legacy	Burden to Others	
		Role Preservation	Concern for Loved Ones after Death	
			Privacy Boundaries	

1. Physical Concerns – This theme refers to the issues that arise from or are associated with the illness itself and from concerns about providing for basic security. Physical integrity can influence dignity and may threaten to, or actually diminish a patient’s sense of dignity. It consists of the four subthemes below:



1a. Loss of Independence - refers to a patient’s inability to perform activities of daily living, due to loss of functional or cognitive capacity, which results in dependency on others.

Functional Capacity refers to a patient’s ability to perform activities of daily living.

Many participants found that adapting to being dependent on others impacted their sense of dignity.

“I’m a very independent person, I’ve always been independent and increasingly, I’m dependent on other people and for me that...(sigh), for others it may not be, but for me that is a loss of dignity. That I have to ask for help constantly.” [RA]

“I could not walk. I could not stand, I used to crawl and go to the bath...And there was nothing I could do to help myself! Chemo is... really, really bad! ...I could not do anything! You know when you can’t help yourself and I’m independent. I do everything and just this one point in life you can’t do anything! You need other people to look after you. ... my daughter said to my husband “Mummy is becoming a baby now!” [BN]

“Dignity is very simple, it is to be able to feed yourself, get up in the morning, go to the shower or bath and go to the loo, brush my teeth...to me that’s dignity. In other words, I could do my own ablutions. At this stage I am reliant on a carer and that disgusting! ...and this is breaking my heart! Being able to take care of myself physically is very important. ... not be able to go to the toilet... it is the worst thing in the world for me!”
[BDM]

“There is no dignity. My soul. (soft spoken) That my soul is being sliced away. Coz of the way I feel over these last few months. It affects me very dramatically. Can’t go to the loo by myself. Got to get a nurse to take me. I can’t walk...got to get a nurse to take me. ...not being able to get up in the morning.” [GSR]

Cognitive Capacity is the ability to maintain one’s mental/thinking capacity. A loss of cognitive capacity was feared by some participants as the worst insult to their dignity.

“My mind is stable and sound and that is my independence and this is my dignity....”
[SG]

“The worst thing for me will be... if I lose my mind that is if I forget what I have been and what I want to do.” [PHR]

“As long as my mind and mouth work. I am good to go. I got the landline and the cell phone and this is all my customers (in this book). I can phone them.” [BDM]

1b. Symptom Burden – this sub-theme refers to the experience of physical discomfort that is experienced as one’s disease progresses. The symptom burden especially pain can be so severe that patients may feel that life is no longer worth living.

“Not being able to cope effectively with the pain, not being mobile, so having to use my wheelchair. The happiest moment is when I’m here and I have no pain and I can just sit here and it’s just absolutely wonderful to have no pain. So a lot of my time is spent in pain, a lot, a lot, a lot.” [RA]

“That is another thing losing control. I can’t accept it! I can’t accept it! I battle with that! I can’t sit here and make a mess in my nappy and then call ____ to change me...” [BDM]

“Chemo, it kills you slowly I would tell my husband “I just need a gun, I just want to shoot myself and get over with this... I can’t do this anymore; I cannot manage anymore... because of so much of pain. ... It was unbearable!” [BN]

1c. Frustration and Dissatisfaction with Medical Care – this sub-theme refers to the irritation, exasperation and lack of trust experienced by patients due to dissatisfaction with the medical care provided by healthcare professionals and facilities. Furthermore, it was noted that in the private sector, the right to basic pain relief was not met due to lack of knowledge on adequate pain management. Short consultation time and poor communication skills left patients feeling unsupported.

“When I’m not diagnosed effectively by my doctors or treated effectively by them. I will go and have a consultation with one of my doctors and he’ll be clearly very much in a hurry, not enough time to see me, and I always feel absolutely lost. I complain about the pain. They don’t take me seriously. They poo-poo it. ...he called me a drug addict. I felt completely undermined, devastated, this is my doctor! Who else can I appeal to? I don’t trust him anymore.then I feel I have no support. That undermines me completely! I put my life in their hands!” [RA]

” The only time I was disappointed was when I used to go to ____ Hospital and they would tell you to go home, and drink water, for months! When you have a serious problem! The one day, I was so frustrated, I threw the file and walked out...” [SU]

“The hospital didn’t give me any good care. Doctors do not record patient’s history properly and the files are confused. I am not getting my treatment. Different doctors are treating me all the time.... In hospital, when I used to mess myself, and the nurses were unhappy with me and they press me and punish me and then I feel I don’t have dignity in the hospital...” [ZO]

1d. Basic Security – this was a dominant sub-theme in this study and refers to the concerns that arises in providing for the basic physiological human needs of food and shelter, and financial and medical needs. This was a predominant concern that adversely impacted the dignity of participants from the lower socioeconomic backgrounds. If these needs are not met, it is difficult to experience dignity in advancing disease.

Food: *“... I was working and now I can’t, and so I can’t get an income for the household...I am sick... (teary). I feel very sad because I can’t support my children now...and I am not getting a grant and yet I am the breadwinner in the family and this affects my dignity as my children are hungry.” [ND]*

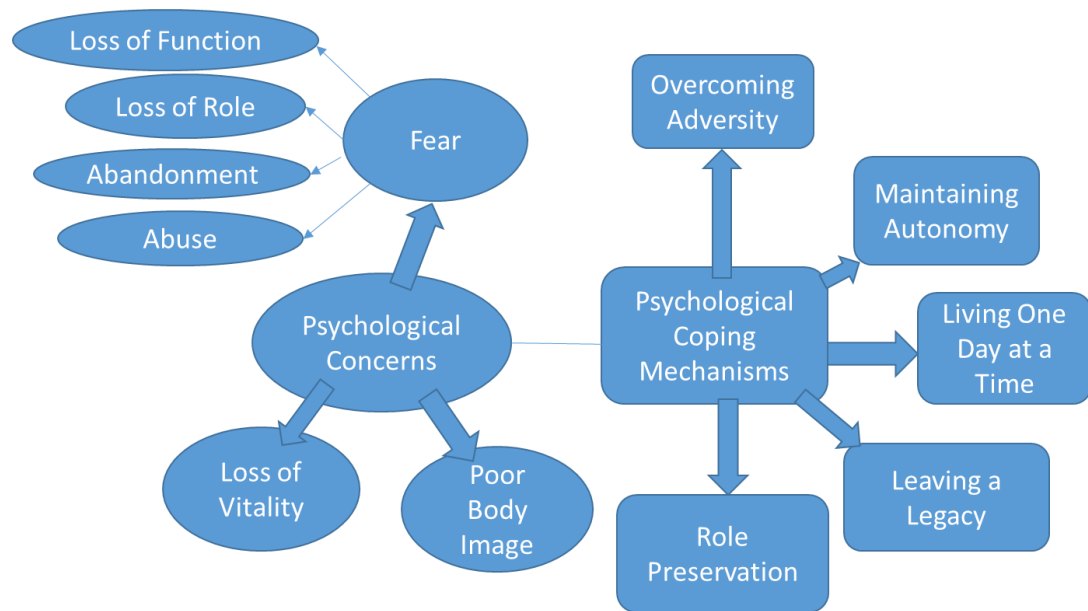
Shelter and Medicine: *“I have children and when their father comes and I say I need some tablets, he refuses and tells me it’s better for me to die...this is the worst thing...the place we live in (one bedroom for four children and patient) is also not big enough and I asked him to extend even one room but he refused.” [TA]*

Money: *“Money is very important to my dignity. I am the bread winner in this house (with my government pension), there isn’t anyone else working.” [ZO]*

Transport/Access to Medical Care: *“My son sometimes leaves me at the taxi rank and I struggle to push my wheelchair (to get to the hospital)” [ZO]*

Access to Basic Medication: *“When I take my pain tablets I feel better but at the moment I don’t have...the hospital did not have” [ZO]*

2. Psychological Concerns and Coping Mechanisms – this theme refers to the mental and emotional concerns participants had with advancing disease that impacted on their dignity and the mental strategies, qualities or attitudes implemented by patients to maintain their dignity. This consists of 6 sub-themes:



2a. Anxiety and Fears Arising from Advancing Disease - Analysis identified mental anguish (worries and fears) arising in the minds of patients as the disease advances, including fears of dependency due to loss of functional and cognitive capacity and fears of being abandoned by medical professionals. Mental anguish also arose with loss of function and role and the potential of being victimized/abused in their vulnerability. Additionally, psychological distress stemmed from loss of vitality and poor body image.

“... I’m scared of that, being bed ridden. I’ll be absolutely dependent on who? I don’t know...” [RA]

“...being abandoned by doctors. They can’t treat me anymore. That would crush me completely!” [RA]

“Some people want to take over my place because I am sick and they are also taking my things that I used to work with. This makes me feel more sick and worry and I don’t get better. These people want me to go to the day care centre because I am sick now...” [ZO]

Loss of Vitality – vitality refers to the inherent life force and liveliness and creative power within man which illness, fatigue or depression diminishes. Amongst African participants, the loss of vitality had a severe impact on their dignity experience.

“I was so strong...they loved me when I was healthy...When I look at the photo, I see how strong I was...I am holding a lot inside. I accept that I am sick now because I can't change what I am, but I am worried when people come to say bad things to me because I am ill... I feel very bad when I see how I was...and how I am now.” [TA]

Poor Body Image – body image refers to patients' perception of their own physical appearance or attractiveness in relation to others or a cultural norm, and this was found to be a challenge with some young participants and participants who were accustomed to an active social life.

“(sigh) My nails, my hair...my beautiful hair fell off. My stomach if you look at it, it's off shape...Now it's cut down and it's not... like right. One side is bulging and the other side is little flat. It's off shape... so when I use clothes you can notice my stomach and I feel like 'Is anybody noticing me?'...I try and cover up, I don't want anyone to see. You know some people just laugh and say you are abnormal or something...” [BA]

“... Not being mobile, so having to use my wheelchair. I think I look more dignified in my wheelchair but certainly not dignified using my walker.” [RA]

2b. Resilience / Overcoming Adversity - refers to the willpower, courage and determination that individuals call on to cope with their experience of advancing illness and to optimise their experience of their quality of life. Most participants in this resilient South African population had an ability to bounce back from the challenges they had faced during the course of their illness with courage, determination and hopefulness.

“So when I was diagnosed, for a couple of days it hit me, and then realization hit me that 'look, you have got it now, now you have to try and fight it!' So, that is what I try to do, I try to be strong and fight it because if you give up and sit down, it is going to overtake you.” [SU]

“.... I don’t allow anything to undermine my dignity. Like when mum sent me to hospital prematurely without involving me, I sat and thought about it, and that maybe it was for my own good...I feel very strong-minded and positive. I feel I don’t have time for negativity...Knowing I did not give up gives me the strength to carry on...determination....” [SG]

“The fact that I am not giving up!” [GSR]

2c. Maintaining Autonomy/Control - refers to having a sense of control over one’s life’s circumstances and choices and how this influences dignity. In this study, it was found to be related to the degree of autonomy the patient feels subjectively, their sense of self. Family turmoil and distress that occurs when a patient is diagnosed with a life-threatening illness also impacted on the dignity of patients. Participants exercised choice to protect their environment and dignity experience.

“...I would think that if people listen to what I think and say.... I used to be very particular about my blood transfusions. I try and check the blood packet and they think you are acting funny... I just need to know it’s been checked... I prefer if they take my opinion into account.” [SG]

“.... the doctor wanted to do an operation to insert pins in my knees... when it happened, I felt a bit shaken, and I was not so confident anymore so I told him I just need time to build trust in my body...I was not ready for surgery and he was fine with it.” [SG]

“My husband’s sisters cried. And I refused to see one of his sisters. I said, ‘I don’t want to see her if she is going to come and cry by me. I’ve done my crying...’.” [BN]

2d. Living One Day at a Time: this refers to the practice of focusing on the immediate present in an effort not to think and worry about the future. This was a common strategy employed by the participants to cope with their advancing disease so that they could postpone their psycho-existential distress.

"I go to my friends and we talk and laugh and I forget about the sickness..., I don't worry. I don't let small things trouble me...NO, NO, NO...and I feel good." [BA]

"I have to listen to what the doctors tell me and I carry on from there. I tell her, don't worry we will take things as it comes...we patients and the doctors we joked, laughed and talked a lot. life must go on...no matter how serious the situation is, keep yourself smiling ... collecting and keeping is not worth it, tomorrow you are dead, then what are you leaving but your name and the good deeds you have done. So, while you can do your best, do good for other people." [SU]

2e. Leaving a Legacy: refers to an individual feeling comfort in knowing that after death they will leave behind something of benefit to others, such as their contributions, accomplishments and connections to life.

"I quite a bit reflect that I have lived a good life. I'm thankful for that, very thankful. I've done a lot of reflection on what I've done, where I've been, my achievements and... that helps. That uplifts me. I'm 67, and been very fortunate. Travelled all around the world. Studying, working, wonderful people, wonderful experiences and I'm very, very grateful for that. Occasionally I do reflect and that boosts me." [RA]

"I can tell the children about my life and tell them to respect themselves and respect everyone. I also taught them how to weave grass baskets." [ND]

2f. Role Preservation: refers to an individual's ability to continue to function in their usual roles despite advancing illness as a way of preserving a sense of dignity congruent to previous roles. This was a strategy that participants who were not severely physically challenged employed to feel productive because their sense of self-worth depended on their ability to perform.

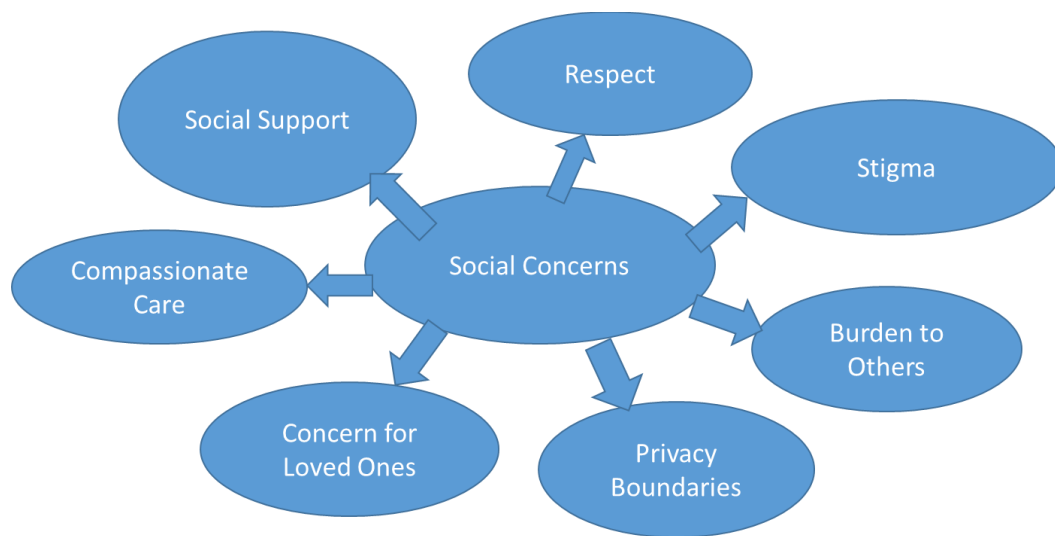
"The ability to work, currently partially, supports my dignity." [GSR]

"There was an issue in parliament and somebody from the press that I knew phoned me up for a comment. That lifted my spirits! Took me back to the kind of work I do..."

eh... enjoy doing. I could contribute again, for a minute or two. I felt like my own self.”
[RA]

“The thing that helps me is to accept the sickness HIV, and I disclose my status to people, and I educate others about HIV. It helps me to become strong in life to talk to others about it. I like to help others!” [ND]

3. Family and Social Concerns - This theme refers to the relationship or social dynamic that influences one’s sense of dignity. This category consists of seven sub-themes:



3a. Social Support: refers to the presence of an available and supportive community of family, friends and caregivers. Social support or the lack of it proved to be a large factor that impacted on dignity amongst all the participants as is described by participants below:

Examples of the impact of good social support structures on enhancing dignity:

“Together with the wife, we support ourselves and uplift each other and the children are very supportive...they always ask: Dad, how are you? What can we get you? Must we take you to the doctor? Take you here or there.... very supportive. As long as I have the wife with me, I am happy...I have my right hand.” [SU]

“My husband supported me ... He used to always make jokes, he never ever looked at me like she is ugly or she is dirty, nothing like that, never ever! He even bald his head the same day that my hair came out...He never ever made me feel insecure or I’m not worthy. All of them my sister in laws, my brothers, my mother, my father, everybody even my husband’s family... They were always supportive of everything.”
[BN]

“A lot of them ask me which way can I help you...Friends and family always phone and ask me what you want to eat, what can we bring for you. Friends also asking me if u want to go anywhere.... so, I don’t feel lonely. I know that there are people still who make me feel valuable.” [BA]

An example of an absence of social support in a highly independent individual who could not take support even though support was offered and available:

A very wealthy, independent, previously active man who lived alone, isolated from his family shared,

“Disappointed in the people I worked with... Life goes on you see! They occasionally phone to say how you doing? ... they’ve sort of forgotten about me in a way. So, that’s been the hardest really. People I worked closely with. Go to drinks, work together, projects. On a daily basis... None of those people contact me.... anymore. I expected more support from them. But they are busy...” [RA]

Lack of social support fractured the dignity of many participants. Expressions of the impact of lack of social support on dignity in impoverished communities:

“I feel like they don’t like me....in December, I went to the farm to spend time at home, but they did not treat me well and I had to return back early to stay here. When my children phoned my extended family to tell them that I am sick, despite being the only female child, not even one person visits.” [TA]

“My daughter was not supporting me and blaming me for her HIV, and she said that she is fed-up of looking after me. And then I felt angry, because I did not realize, I was

a burden to them so I wanted to take the tablets to overdose. When people don't respect me, I feel I have no dignity! Being disrespected is worse than being in this wheelchair" [MA]

"Sometimes I feel like killing myself. When I was not able to help myself, and I was not walking, not even one of my family helped me." [ND]

Vignette Illustrating the Disillusionment Experienced Due to Lack of Social Support:

An elderly male with cancer is disillusioned as he has dysfunctional family relations and an unsupportive community despite spending his entire life providing, caring and building a home for his family and supporting the community by opening a crèche for community mothers so that they could go to work. Instead of providing support and care, the family and community rejects him and attempts to steal his property and belongings. His wife does not support him and his son is a drug addict who steals the grant that he receives. Additionally, he also has a daughter who is an alcoholic. The only support he had received was from his daughter, who had died of AIDS. *"Some people want to take over my place because I am sick and they are also taking my things...This makes me feel more sick and I worry and I don't get better. These people want me to go to the day care centre because I am sick now. Sometimes my wife is unhappy because of my condition. I cry because the family does not treat me well. I am worried about my son because my life relies on him. My son sometimes leaves me at the taxi rank and I struggle to push my wheelchair. My wife has no respect (crying). ... I can't do anything. I must stay. I have to listen to what they say to me. I don't like what they say to me. It's hurtful but I have to take it...(crying) Instead of this life, I would choose to die. When I collect my grant and bring it back home, my family steals the money and I end up with not a single cent. Month end my four sons come here and take money and go. I put my money here (tied to my arm) and my son steals it whilst I am sleeping...he shaves me and when I fall asleep, he steals it. And then I have no money to go to the hospital, and the doctors don't understand."* [ZO]

3b. Compassionate Care refers to care offered when interacting with a patient based on a deep awareness of another's suffering and the pure intention to provide relief of this. The following patients expressed appreciation for the attitude of kindness, professional behaviour and valuable dialogue and compassionate care expressed by their health care providers, including hospice staff.

"The nurses spoke to me and handled it very professionally. The first time I like passed a stool I was like.... horrified and they said, 'No, these are things you can't help its natural'...and so I sat and thought about it... I actually have excellent doctors who listen to what I have to say and they educate us more" [SG]

"I am grateful cos the staff looked after me better than if I was in a private hospital.... I was well taken care of... they made sure I tried to eat, if I could not get up, they bathe me and put me back to bed... they were more than family although there were so many shifts of nurses they were all 100%... the nurses and doctors, we joked, laughed and talked a lot." [SU]

"I am happy when the hospice comes to visit me because ...I open up and tell everything when they come to visit...(smiling). So, I feel my dignity is supported when I can speak and people understand and listen to me. I am holding a lot inside and I can share this with hospice when they come to talk to me... I feel better when I am guided by hospice on how to eat and drink. When I was vomiting and they tell me to eat a little at a time I do it, and I feel better." [TA]

3c. Respect – this refers to the way of treating or thinking about a patient, the attitude of regard for a patient's feelings, wishes or rights, as displayed by medical staff, family and society and the supportive impact it has on the dignity experience of participants.

"They speak roughly... I don't get respect from the doctors at the hospital. The way they treat me, they make me feel like crying." [ZO]

"That is how the nurses and doctors took care of me.... lot of respect and lots of love and so I really appreciate that..." [SU]

“And some of the people don’t respect me and they take me for granted and don’t respect me. When they show me respect I feel better, and when they show me that they don’t respect me, I get more sick.” [TA]

“I think it’s something deep inside. It’s there but can definitely be affected by others by their behaviour. Definitely...your sense of worth is also affected by how other people treat you... it certainly is deep inside but very vulnerable to outside attack.” [RA]

3d. Stigma - refers to the strong feeling of disapproval that people in society have about something be it a circumstance, quality, person or illness. Stigma is based on a set of negative and unfair beliefs. It was found that HIV is still highly stigmatised in communities and the diagnosis of cancer was also found to be stigmatised in the Indian population.

“The neighbours sometimes stigmatise me because I have HIV. I remember one time that hurt me about the neighbours: I am planting and the neighbours’ animals destroy my garden and when I told the neighbours about it, they shouted at me and screamed out my status. This makes me very sad. Sometimes the family affects my dignity because they don’t share not even a spoon.” [ND]

“When I touch food, the people are not happy and will not eat it. Other people they don’t eat, where I am eating or use the plate or cup that I am using because they know that I am very sick. They don’t even want to share the toilet with me. I disclosed to them that I have HIV and cancer and TB...they don’t accept me. Now I am losing weight and my clothes are not fitting me and when I take the clothes to give to others, they don’t accept it and this affects my dignity.” [TA]

“Some of the Indians they lock themselves in and they don’t live. They give up as soon as they hear (they have cancer) and they think it’s the end of the world and they don’t tell others... But there is nothing to hide! And they also isolate themselves...” [SU]

3e. Burden to Others is a sub-theme that derives from the distress a patient experiences from having to rely on others for personal care or medical management or from a fear of potentially having to rely on and becoming a problem to others. This was found to be a source of great distress amongst participants.

“These people want me to go to the day care centre because I am sick now. I am not happy about that. ...I don’t want to worry my wife. I try to do things for myself. I wake up at 4am every morning and I go to the bathroom...” [ZO]

“Sometimes I can’t bathe myself and the neighbours come to bathe me and then I feel life is not worth living.” [TA]

“I feel sad especially when I need assistance to help me especially because I can’t stand or walk and if I ask someone I feel like I am a troubling them.” [MA]

3f. Concern for Loved Ones After Death are the fears or worries that a patient experiences in anticipation of the burden and loss that their death will impose on others. This was a common concern of young participants with advanced disease who had young children.

“Shame (crying) It’s not fair on my son! I am worried about my wife and child and what life am I leaving them.” [GSR]

“...the thing that got me through it was my daughter... There is no way she is going to live without me. She cannot survive without me. She can’t, she was too attached. I said there is no way... I have to do something and get myself sorted out because she cannot live without me, ... I had to live for her.” [BN]

“I am fighting for my children because they are young...18 and 12.” [TA]

3g. Privacy Boundaries: this refers to an influence on a patient’s sense of dignity, when their personal space is infringed upon, when receiving support. Participants

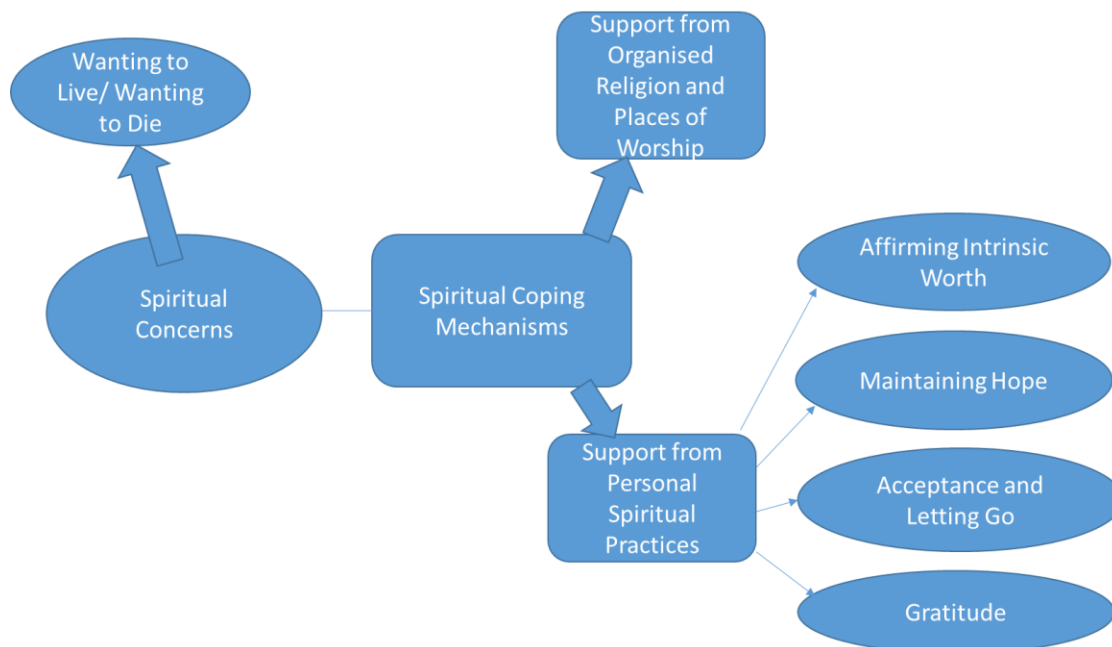
described the mental anguish experienced when their privacy boundaries were initially challenged, however with time they adapted and loosed their privacy boundaries.

“... having people look at me and pity me. If I stop in a shopping centre or even a medical centre, people rush into me and help. It is very kind and sweet. That’s not the way I lived.” [RA]

“...that was the first time in my life I wore a male nappy. Oh my God! I am unfortunately used to it now, but do you ever get used to that? No! And that time when I was lying in bed and I had to call the sister to change me, that was the worst thing in my life.” [DBM]

“I would feel I had no sense of dignity if I could not wipe my own bum.” [GSR]

4. Spiritual Concerns and Coping Mechanisms – this refers to the existential issues and personal spiritual awareness, attitudes and actions that patients practice to optimize or preserve their dignity experience. This consists of 3 subthemes: support from personal spiritual practices (affirming intrinsic worth, maintaining hope, acceptance and letting go, gratitude); support from organized religion and places of worship and Wanting to Die/Wanting to Live.



4a. Support from Personal Spiritual Practices – this refers to the personal spiritual awareness, attitudes and actions that patients practice to optimize or preserve their dignity experience. This stemmed from individual quiet reflection, private prayer and meditation leading to self-discovery and search for greater meaning in life's experiences.

1. Affirming Intrinsic Worth: is a subtheme which expresses that, in spite of one's illness the essence of who one is, one's intrinsic untouchable dignity, continues to remain intact. The following accounts from participants captures their affirmations of intrinsic worth.

"I think dignity is something inside you and not something that people can give and take away from you. If you have pride in yourself, then nobody can take that out of you... You must have pride to keep your dignity, so I would say that that is something you can't take away, come the worst situation. You always think of yourself as somebody, a somebody, not a nothing!" [SU]

"I have a lot of time to sit by myself and think and I DO meditate a lot...you need to be comfortable with yourself... I like the peace and quiet...YOU ALLOW a situation to make you feel a certain way....so I don't allow a situation to have power over my feelings. I maintain that calmness. I don't allow my dignity to be undermined." [SG]

"I believe I can hold my dignity and no one can take my dignity away from me." [ND]

Vignette of an Individual Whose Personal Spiritual Practices Helped Her Retain Her Dignity Under the Most Challenging Circumstances:

SG was a 31-year-old woman who was diagnosed with Thalassaemia Major from birth, requiring weekly blood transfusions, who acquired HIV in her childhood through blood products. She subsequently developed osteoporosis, shingles, CMV, blindness in her right eye and when I met her she was bed-bound from bilateral knee and ankle fractures and multiple spinal fractures. She was brittle and her body seemed to be literally

crumbling but her spirit was delightful and admirable beyond measure. She commanded such autonomy, respect and mastery and lived a life of dignity with circumstances that most would declare as hopeless and a life without dignity. She attributed her resilience and acceptance to her quiet reflective time, dialoguing with herself and meditation. Below are some of the spiritual practices that she employed to retain her dignity:

1.Reaffirming Intrinsic Worth: *“Your soul is important and it is important to take care of that aspect of your health, you need to be comfortable with yourself because if you can’t enjoy your own company, how can you expect others to enjoy your company. Meditation is getting in touch with your inner soul and relocating that happiness within you, and not looking for that happiness in other things and people... I practice with meditation not to allow anyone or anything to affect me.... they say that you allow a situation to make you feel....so I don’t allow a situation to have power over my feelings, I maintain that calmness.”*

2. Spiritual Support/God: She had a real endearing relationship with a Higher Source of support. *“There are days when I get tired and I always have these conversations with God, saying you know I am tired now please stop.... please put it on pause...”*

3. Finding Meaning in the Numerous Challenges: When challenged she stopped, distanced herself from the situation, and reassessed it from a different perspective and found meaning and acceptance in all circumstances. When her privacy boundaries were challenged for the first time, she would not allow herself to stress because she believed stress to be a killer: *“I guess through meditation.... I just let go. You have got to choose your battles. I feel very strong minded and positive... I have no time for negativity... I can talk myself out of being angry and I can talk out of being depressed. I think there is so much of things that are worse and I always say to myself, I am lucky for what I got, I can still function. For me my brain is my prized possession, my brain is what I am, it does not mean that because I am in a broken body, I can’t function fully, my mind is stable and sound and that is my independence and that is my dignity... I may whine and complain about aches and pains, but I won’t feel sorry for myself because I know I have lost friends to cancer and lupus... I always feel like I was lucky to get what I got. You can’t die with dignity but you have to live with dignity, a dignified life. For me when I am at that point I*

feel like I am at the bottom and the only way to go is up, I feel most of your illness is 99% of your attitude and positivity and the vibes that you give out.... if you give positivity, you attract positivity so I try and just ...stay calm."

Her advice: *"You have to look after the spiritual part of your life to lead a healthy lifestyle. People don't realise it and they need to be taught the importance of it."*

2. Maintaining Hope is associated with an ability to see life as having sustained meaning and purpose. Despite the extreme physical challenges, the participants of this study were resilient and hopeful, defying medical prognosis.

"As I said, they said two months' time, you will die.... And in two months' time I am going on pilgrimage. I am going to go there, and I made my intention....and I am going with the intention and if Almighty accept it, maybe I will have few more years to live...(laughs)." [BA]

"I was completely finished but there was always something in the back of my head, telling me that...(sigh).... I never ever reached that point where I said, 'it's gona end forever', they gave me till December to live... even then I like didn't believe them. This inner knowing. I don't know, but just something inside you, it guides you and it tells you which direction to go in. And it is something that I always listen to and just that inner thought, I can't even explain it, I've been through fighting with the doctors and challenging them and everything." [BN]

"I don't lose hope, when I have a problem...." [TA]

"... when I was asked by my wife, if this is as good as it gets, I said 'no'. The tumour was still there but I was still fighting it." [GSR]

3. Acceptance and Letting Go: this refers to an attitude expressed by patients of assenting to the reality of a situation and recognizing and understanding a situation without attempting to change or protesting it to control life's changing circumstances.

The following are examples where acceptance is expressed as a coping strategy to maintain one's sense of dignity:

"... Life also changes every day... when the doctor told me, we can't do anything for you anymore, it was a shock for me! Because it was a death penalty, but I accepted it, because I thought what do I want to do anymore? Because I am still guiding people, I am helping my family, talking to my friends. I can read the bible and pray, I got a good pension to live on..." [PHR]

"If you are going through a serious illness at the beginning, it hits you hard when you first hear about it but once you settled in and understand that you have it, then you cope with it, then its fine. Even if they tell you that you have few months to go? That's fine." [SU]

"...and I think now I have taken a more spiritual turn in life where I meditate a lot so they say pride is not a good thing...I have been handing over to nurses mentally... I have learnt to let go...and not be so controlling... I talk to myself a lot in my head and I say 'get over it immediately and don't stress about it'.... through meditation.... I just let go. You have got to choose your battles." [SG]

"I understand about my sickness. I have to accept it. My sickness is there and I cannot change it." [ZO]

4. Gratitude – this refers to a quality of being thankful and a readiness to show appreciation for and return of kindness. In these cases, participants were grateful for their circumstances in comparison to others who they perceived to be in more challenging circumstances and this helped them accept their changing state of health and cope better.

"I am lucky for what I got. I can still function. For me my brain is my prized possession. My brain is what I am. It does not mean that because I am in a broken body, I can't function fully. My mind is stable and sound and that is my independence and that is my dignity.... I have lost friends to cancer and lupus..." [SG]

“There are people worse off than me so I must thank God that I am in this position where I am better off than a lot of people out there.... we thank God we have bread to eat. We got luxury food. People are looking in the bin for food. They are begging. We should think of them first. Yes, looking at the bigger picture... our prayer should be for them...if you have two of something, help them with one...better to give than to receive. We grew up in a hard way... I am grateful for my parents for bringing me up in that way and now when people tell me these are hard times we going through, for me it's easy.” [SU]

4b. Support from Organised Religion and Places of Worship: refers to the practice of seeking comfort in one's religion and religious congregation. This was a predominant theme in this South African population. As social structures fail, support is sourced from faith based structures.

“I must pray and thank God that in time I got in contact with the doctor and got into the right hands... We just believe and put our trust in God and that is what gives me strength to know that I have a God that keeps his hand over me.... Yes, faith is very important. If it was not for the grace of God, I will not be here. I must give them a testimony when I go to church of what God did for me in my hard times. God undertook and stood for me all the way. I got a lot of support from the brethren in the church and the pastor. They used to always come and pray a lot in the hospital and always encouraged me.... people come and pick me up now and take me to church and bring me back home.” [SU]

“I was up high and now I am low, but in my religion, I am very high...I think people respect me and want to listen to me, my children, family, friends they all think I am a good guy. My belief, my Christianity uplifts my dignity and also I grew up in a very good house, my father and mother were very precious and religious people and they gave me the opportunity to walk the life...” [PHR]

"I know no one can help me, only God can help me. Only prayer is boosting me. I pray and God gives me strength. I believe that God is there with me. ... when I go to church the words of God boosts my mind...when I am with people and I go to the church I feel well and the mind is better." [ND]

"When the doctor said to me I got prostate cancer, I told myself 'Oh thank you Almighty Allah for all the years I lived happily, everyone has to go and it's my turn so Almighty you can take me anytime...I must thank Almighty at this age I see, I drive, I move around... Slowly He brought me to this position, and so I thank Him and I depend on Him, FINISH! He wants to help you, He will send you help... so now Almighty, just guide me." [BA]

"When I take the bible and read it...it uplifts me....and I attend the church every week...The family also makes me feel happy but not as much as when I am at church. The people from church give me good support, they phone me and give me good words for counselling and they help me and make me relax." [MA]

4c. Wanting to Die/Wanting to Live: The following are variable patients' responses to the question "Some people feel life without dignity is a life not worth living, how do you feel about that?" Patients willingly volunteered accounts of episodes in their illness when they wished to die. They felt safe to express this information, but stated that they would not act on these thoughts. Comments from all patients are included in this section.

"I'm giving myself a year to get better. I'm not prepared to go like this. I'll do that course (euthanasia) if I have to. I'll give myself a year." [RA]

"No I am too strong a person for that!" [DBM]

"I push them away because those are bad thoughts." [GSR]

"I don't think I will kill myself if my dignity is bad." [ND]

"Sometimes I can't bathe myself and the neighbours come to bathe me and then I feel life is not worth living. But I won't take my life. I will pray!" [TA]

"I think that I have accepted now... I won't choose to kill myself." [MA]

"No I don't think so! There are plenty ways in which you can uplift yourself as well. A lot of things you can do to take your mind off the negative thoughts. Think positive and carry on." [SU]

"NO, I don't believe that ...to hell with everybody man... me and my Creator is enough... I won't want to die." [BA]

"As I said, I just wanted to take a gun and shoot myself (laughs) when I was in pain and weak from the chemo. Now when I look back, I think, like why did I think that, I was so stupid." [BN]

"I am very against suicide...I read... about dying with dignity where you get to choose when you want to be put down and there are places where you can go to control my death...I happened to watch an episode of HOUSE MEDICAL...they said "You can't die with dignity but you have to live with dignity, a dignified life". And that is when that whole idea went out of my head and suicide is not an option for me It's not a weakness. Everyone sees it differently and only one who is in that situation will know what it feels like to be at such a low point. For me when I am at that point, I feel like I am at the bottom and the only way to go is up so after that it will get better and I feel most of your illness is in your head.... its 99% of your attitude and positivity and the vibes that you give out.... if you give positivity, you attract positivity so I try and just ...stay calm." [SG]

B. Results of the Impact of Dignity Therapy and Guided Imagery on the Dignity Experience of Patients with Advanced Disease

1. Quantitative Feedback from Feedback Questionnaire

Table 3. Responses from participants to the Patient Feedback Questionnaire:

Feedback Question	Strongly Disagree	Disagree	Neither Agree/Disagree	Agree	Strongly Agree
1. I have found the Interventions to be helpful to me	-	-	-	5 (42%)	7 (58%)
2. I have found the Interventions to be satisfactory	-	-	-	6 (50%)	6 (50%)
3. The Interventions made me feel that my life currently is more meaningful	-	-	1 (8%)	5 (42%)	6 (50%)
4. The Interventions has given me a heightened sense of purpose	-	-	-	5 (42%)	7 (58%)
5. The Interventions has given me a heightened sense of dignity	-	1 (8%)	2 (17%)	1 (8%)	8 (67%)
6. The Interventions has lessened my sense of suffering	-	2 (17%)	-	4 (33%)	6 (50%)
7. The Interventions has lessened my feelings of anxiety and depression	-	1 (8%)	-	4 (33%)	7 (58%)
8. The Interventions has increased my will to live	-	-	2 (17%)	5 (42%)	5 (42%)
9. I believe the Interventions has or will be of help to my family	-	-	1 (8%)	4 (33%)	7 (58%)
10. I believe my participation in the Interventions could change the way my family sees or appreciates me	-	-	3(25%)	4 (33%)	5 (42%)
11. I believe my participation in the Interventions could change the way my health care providers see or appreciate me	-	-	1 (8%)	7 (58%)	4 (33%)

All participants felt that the interventions were helpful, satisfactory and created greater meaning in life and a heightened sense of purpose. A participant who felt she had a practice of always finding meaning and maintaining her dignity in life was neutral in her responses. Most felt that their dignity was heightened and suffering lessened, except for a participant who could not come to terms with his loss of functional capacity. Another who practiced acceptance of life's circumstances stated that he does not suffer. Majority stated that the intervention had lessened their feelings of anxiety and depression, except for one who stated that she was not depressed. The interventions had increased the will to live, and was stated to have potential benefit to family members and in the way family members and healthcare providers would see and appreciate patients.

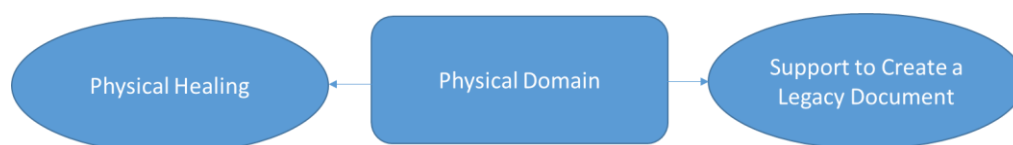
2. Qualitative Feedback from Feedback Questionnaire Based On Responses to Enquiry into How the Interventions Were Experienced

The interventions had an impact on the Physical, Psychological, Social and Spiritual Domains of the participants' lives and these emerged as the four themes with various subthemes.

Table 4. Themes and Sub-themes of the Benefits of Dignity Therapy and Guided Imagery

Physical	Psychological	Social	Spiritual
Physical Healing	Feeling Understood and Valued	Beneficial to Family: 1.Sensitising Family to Understanding Patient 2. Sharing Life's Lessons with Family 3. Personal Benefit Will Support Family	Improved Self Esteem/Worth
Support to Create a Legacy Document	Reflection, Learning and Appreciation	Improved Relationship with Healthcare Workers	Self-Awareness
	Lessened Sense of Suffering		Spiritual Healing
	Lessened Anxiety and Depression		Hopefulness and Increased Will to Live
			Greater Acceptance and Letting Go

1. Physical Domain – this refers to the benefits of the interventions for the participants on a tangible level and included an experience of perceived physical healing and support to create a legacy document.



1a. Physical Healing – this refers to the medical benefits experienced through the interventions. With the intervention, participants experienced muscle relaxation and greater physical strength and lesser pain in the body as illustrated by quotes below:

“I now feel strong in my body and before I was feeling weak.” [MA]

“I feel very much relaxed...and my body is feeling relaxed after listening to the therapy... I feel that my legs are feeling strong...I feel my muscles will work now. I feel more healed...” [TA]

“...doing the relaxation and meditation you said I must sit and relax the head and neck and I feel the muscles is relaxed and the pain has settled in the neck.” [ND]

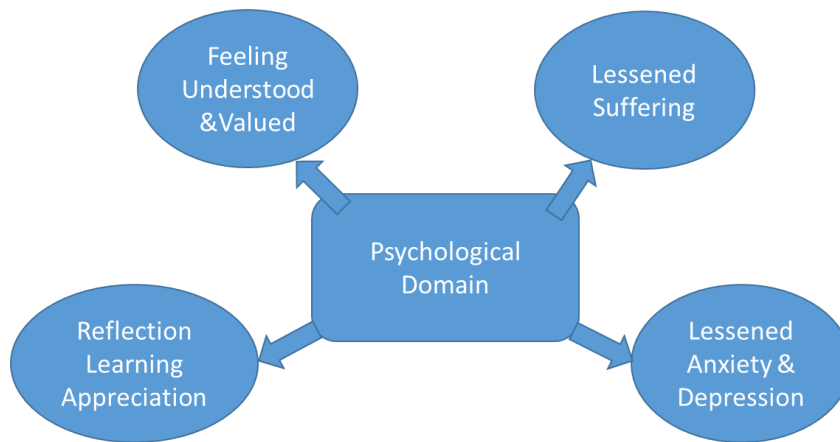
1b. Support to Create a Legacy Document – participants felt supported to create a legacy document, that would serve as a reminder, firstly to themselves and secondly to their family of their accomplishments and strengths in life.

“To me this is meaningful because I have learnt about my life and I have remembered – by remembering my olden days and achievements even today... and I will keep it at my bedside and read the document all the time to remind me of myself and I will forget everything else.” [ZO]

“Maybe someone will read this and it will make them think. I feel happy that I did something in my life...Almighty helped me to think straight... because I gave old poor people a slice of bread they remember me and give me a big smile when I see them.” [BA]

“... look at what I said, I would not say this to anybody unless you came and asked me. It helps when you read it back... a lot and it makes you more positive looking at everything” [BN]

2. Psychological Domain – this refers to the benefits of the interventions on a mental level for the participants of the study and these benefits were manifold:



2a. Feeling Understood and Valued - Speaking and being heard was therapeutic for the participants and helped them feel understood and respected as a valuable individual.

“It’s been therapeutic! I have been able to get things out of me and have someone analyse them and help me see them in a different perspective.” [RA]

“...the thing that encourages me is that the hospital doctor came and saw me, so I have faith that the doctor knows our needs at home.” [ND]

“Speaking out and getting out all that I have inside helped...” [ZO]

2b. Reflection, Learning and Appreciation – the intervention helped individuals to reflect on the meaning of life and extract valuable lessons from their life’s experience and the interventions.

“It forces you to stop and take stock of your life and to reflect and makes you think more about the more important things in your life...instead of moving forward and not learning...” [SG]

“Because it reminds you of who you are, what you capable of...I try not to think of what I went through, it’s painful but at the same time it shows me all the positive stuff that happened. It’s easy to forget.” [BN]

“It opens up my mind. I began to think about other things in life other than myself. You lie here day in and out and feel sorry for yourself, and then with something like this you think these other things mean life!” [DBM]

“The guided imagery was very appropriate and useful to put things into context...takes one out of oneself.” [RA]

2c. Lessened Sense of Suffering – participants experienced less distress and feelings of hardship about their experience of advanced disease after undergoing the intervention.
“When I started to speak about myself I felt better about my life and so it lessened my suffering.” [ND]

“...because when I am placed in a situation I don’t like, I can now stop and distance myself from it and reassess it and relook at it from a different perspective so it does not stress me so much.” [SG]

“...it actually calmed me...I was restless, thinking when the end will come but now you don’t worry about it, you are not at a dead-end road...you are now actually opened so you can do what you want, go where you want, you not scared of anything.” [SU]

2d. Lessened Anxiety and Depression – the interventions decreased feelings of isolation, sadness, anxiety and fear related to their life-threatening illness.
“...before the interviews I was even asking the priest to pray to stop the spirit to think to kill myself but it did not stop. But the time I came here, it healed. My nephew asked me are you still wanting to kill yourself? I said no when I went to hospice the thing is gone...I was so happy to come today.” [MA]

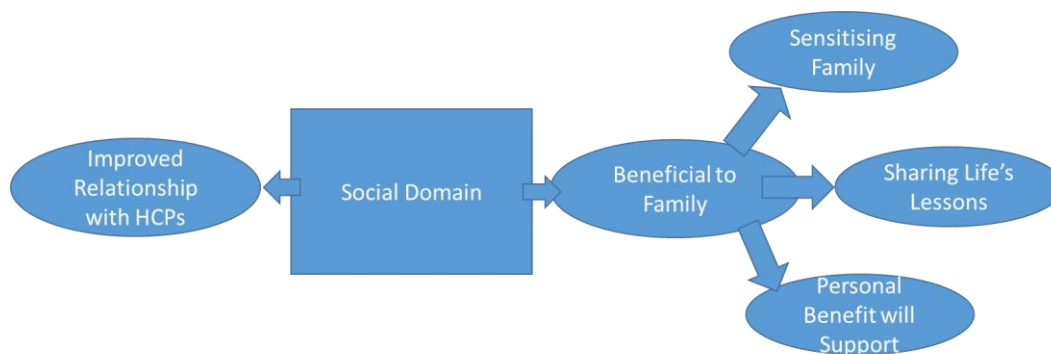
“things are a bit clearer than ever before – I don’t feel so isolated.” [RA]

“It reminded me to stop being afraid.” [BN]

“Nothing makes me sad or scared now.” [TA]

“I realized I was depressed...and I feel better now that I see through the crap...this was the main thing it achieved.” [GSR]

3. Social Domain – this refers to the benefits experienced by the family and healthcare providers by the participant engaging on the intervention.



3a. Beneficial to Family: the participants felt that 1) their family will benefit by their engaging in the intervention as they will be sensitized to the participants' experience of illness, and 2) can learn from their legacy document and the guided imagery, and 3) the participants' benefit will have a ripple effect on their family.

- **Sensitising Family to Understanding the Patient**

“Yes it will help my family so much...if they see this paper they will give me more support...this intervention can help with stigma. Because this paper is me and what I like and what I want to change!” [ND]

“They will read and this is the truth and then they will realise who I am. Then it will help the family change their minds and they will understand what I am feeling.” [ZO]

“... they need to put themselves in my situation. When they read it, they will be very proud of me.” [BN]

- **Sharing of Life's Lessons with Family**

"There are things I may not be able to convey to them but they will get the gist of it when they read this document. It will be a document that can affirm the things I want. We all need to open our eyes and see there is a different way to look at things.... and stop worrying about small stuff." [SG]

"...the guided imagery, yes to my family, to people outside that don't know me even if they read that, it will give them courage, hope and make them feel free, not burdened by everything of the world. It will help me a lot and my family later as well." [SU]

"They see through me now. Why I did some things my way." [PHR]

- **Personal Benefit Will Support Family**

"... they were stressed about me and now they are happy because they see that I am happy with my life.... They will appreciate me more." [MA]

"...you helped me think about other things that are important in life – besides being a pity party, so they can benefit." [DBM]

"Even the family read the paragraph on the guided imagery and it helped." [GSR]

3b. Improved Relationship with Health Care Providers – the interventions impacted beneficially on the relationship between the participants and healthcare providers.

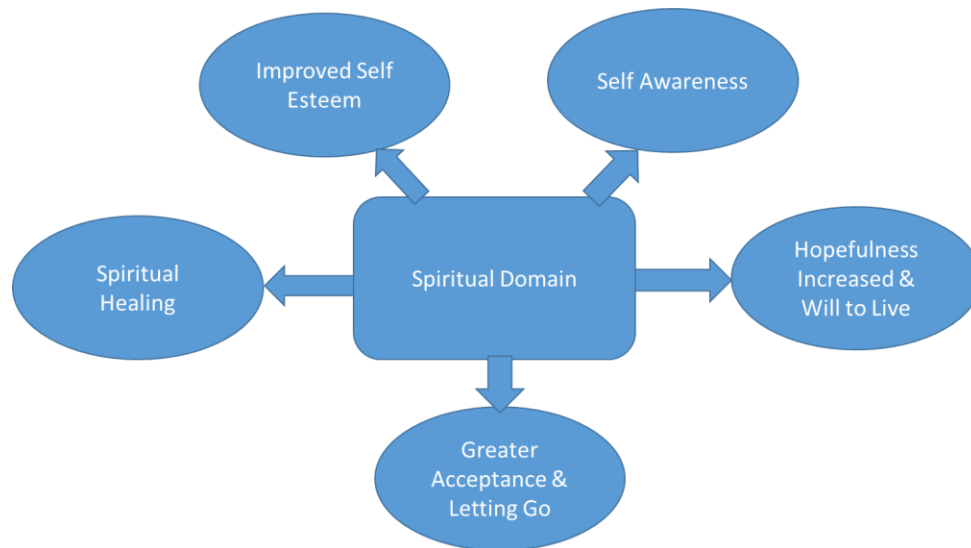
"Health care providers can feel happy when they see that I am happy because when they see the client is not happy they are also not happy and they are also not proud of their work." [MA]

"I think that even the healthcare workers will be encouraged to be good all the time when they read this and will treat me well." [ZO]

“It will change how others see me because I will change how I see myself – my confidence in myself.” [SG]

“Even the people from hospice if they see what you have done here and how things went they will appreciate it more cos they will find me more at peace. It is normally hard to deal with someone who are angry, but because my thinking has now opened up, they will understand me better. It’s a two-way thing. A lot of people want to receive but give and you will receive.” [SU]

4. Spiritual Domain – this refers to the existential benefits that participants experienced from the interventions.



4a. Improved Self Esteem/ Self Worth – participants experienced improved confidence and pride in their worth and abilities.

“And the guided imagery changed my mind... now I change the way I am thinking. I want to be proud of myself now... I feel I now have got back my confidence... I feel stronger and I want to keep this dignity.” [ND]

“Now I learnt to be proud of myself” [MA]

“...now life is more meaningful versus before the intervention. I realised what I achieved and that I am more than what is happening to me... it improved my dignity and worth.”
[GSR]

4b. Self-Awareness – this refers to being aware of who we are, through introspection and the ability to recognize oneself as an individual separate from the environment and other individuals. Self-awareness brought a sense of freedom from the failing bio-psycho-social structures that surrounded the participants, knowing that they were greater than their body, fears and supports.

“...being made aware of what is going on and who you really are, ...you must not be sorry for yourself. You must always be and try to be a good example, not a sad or a bad example... You must have a purpose and people can look at you and they wish they could do the same and this reminded me to do that.” [PHR]

“... the last bit of the guided imagery speaks to me, telling me who I am, and what I am and telling me how I can make myself feel lighter, purer and at the end of the day not worry about the things outside of me, so it's very inspiring to me – ... plus it calms you down, the more you read it, the calmer you feel. Now I can stand up with head held high and say I am going on; this is who I am – this is all because of the guided imagery...makes you think... it opens your mind to things I did not know. Now you feel freer and the worldly things mean nothing even the body means nothing, the spirit goes on...the body can die that is fine your spirit goes on.... your life.” [SU]

“...also the guided imagery and meditation part which I loved because for me meditation is getting in touch with your inner soul and relocating that happiness within you and not looking for that happiness in other things and people. ... we lose the plot along the way... It has affirmed things I have believed in, like your soul is important and it is important to take care of that aspect of your health.” [SG]

“... I like the guided imagery very much so. Going through each step was very peaceful. This was the main thing that helped. This improved my sense of self more than the life

story. I realized that I was more than the body and its illness and I have to get out of this.”
[GSR]

4c. Spiritual Healing – this refers to a restoration of existential health from an unbalanced or damaged existential state. In this spiritually aware South African population, this was a common benefit experienced through the psychotherapies in this study.

“I got healed from the spirit with the whole thing... when I was alone, I used to cry and now I am no more emotional.” [MA]

“...and the mind is thinking good after the relaxation.” [TA]

“Now I can be at ease...there are still openings to what you never understood in your life... the guided imagery – it opens things to you that you did not know, so you become lighter and free and you can go on.” [SU]

“The guided imagery was nice, very relaxing...I never thought I will ever be so relaxed and good thoughts flowed. When I was in hospital when I completely broke down and cried I felt like my body and soul has detached. My soul has detached from my body coz it can’t handle the pain anymore, and I need my soul to get back. I thought I should go to the beach and have my head in the water and get my body and soul together. So this was helpful...a balance of body and soul....” [BN]

“It’s a necessity because you have to look after the spiritual part of your life, to lead a healthy lifestyle.” [SG]

4d. Hopefulness and Increased Will to Live – after the intervention participants expressed an optimistic attitude of mind with renewed purpose and expectations of more positives outcomes going forward and an increased will to live.

“...now you feel you want to go on – you cannot stop here ... I feel I now have a better chance of pulling through what I am going through. And whatever is in me I don’t even worry now...so now this is what I am about – don’t look down, look up and carry on.” [SU]

“...now I feel like I can start some business even if I am sitting in a wheelchair, like I want to open a garage when I get some money...” [MA]

“...cos it reminded me I have so much more to do....cos all the questions you asked me about my legacy....no I have to leave a better legacy than that now. I have to add more to what I want to do.” [BN]

“Yes it is because it opens up your mind to other things, it gives you a new dimension in life. I feel there is more to life than just lying here feeling sorry for myself. I had purpose and I still have purpose.” [DBM]

4e. Greater Acceptance and Letting Go – refers to an assent of the reality of their state of health and the process without protesting or attempting to change it. This brought relief from the non-productive psycho-existential distress that crippled participants.

“I will take time with my family and tell them I will not die when it’s not the time. I will die when it’s the time. God knows.” [TA]

“Yes, like yesterday when I let go and was less frustrated at the hospital as I sat and thought about it, I said no, so every dark tunnel has a light at the end, and then things opened up.” [SU]

“...before the interviews I was thinking of killing myself but when I came here, I felt stronger and I accept the situation and how it is now.” [MA]

The Legacy document produced from Dignity Therapy and the Guided Imagery had a deep impact on the participants:

Additional Comments on the Legacy Document:

“...this intervention can help with stigma. Because this paper is me and what I like and what I want to change!” [ND]

"I will take the legacy document home and keep it at my bedside and read it all the time and you will see. I will change when you visit me again..." [ZO]

"... if people read this legacy then 1,2,3 people will start thinking deep and say this is how this fellow lived his life and they will learn." [MB]

Additional Comments on the Guided Imagery

"I like the guided imagery very much so. Going through each step was very peaceful. This was the main thing that helped. This improved my sense of self more than the life story. I realised I was more than the body and its illness and I have to get out of this. Even if we did not do the other questions and did this, it would help. Even the family read the paragraph on the Guided Imagery and it helped." [GSR]

"...I never thought I will ever be so relaxed and good thoughts flowed. When I was in hospital when I completely broke down and cried, I felt like my body and soul has detached... coz it couldn't handle the pain anymore...I thought I should go to the beach and have my head in the water and get my body and soul together. So this was helpful...a balance of body and soul...." [BN]

"It must be built into one's daily programme, think about it, go through it, that's it! It must be part of your life and it will definitely help with your dignity. So it is better when someone reads it to you. Close your eyes, listen, relax and participate in it. For all people with illness, it will be useful. The mind-set changes. I think it will be good if all hospices can use it, it is short, a few minutes, won't take a lifespan and it is something to fall back on when you feel downgraded, read it or even you can put it on a disc, slot it in and then you can listen perhaps with soft background music and a bloke or woman with a very good voice and when they read it with feeling... When you have a family meeting you can say 'Just stop there, just listen to this, just listen that's all', 10 minutes and then finish, not even that long..." [PHR]

“... you have to look after the spiritual part of your life, to lead a healthy lifestyle. It (Guided Imagery) gives you confidence and helps you accept your situation easier. So when I accept myself, others will accept me.” [SG]

Summary:

This study provided a comprehensive understanding of dignity in patients with advanced disease from a South African perspective. It also highlighted, quantitatively and qualitatively, the numerous benefits of Dignity Therapy and Guided Imagery in enhancing the dignity of patients with advanced disease.

5. Discussion

The twelve participants provided high quality and information rich data contributing to a comprehensive understanding of the foundations and impediments to the dignity experience of patients with advanced disease and an empiric appraisal of the dignity interventions implemented in this varied South African population. The study population included an approximate mix of age, gender, disease and socioeconomic and cultural variability that added to the generalizability of our findings. Advanced disease included terminal cancer and Stage IV AIDS, with comorbidities that included congestive cardiac failure, cor-pulmonale and paraplegia.

6.1 Acceptability and Relevance of the Study in a South African Setting

From the two sites, there were no refusals to participate and no withdrawals. The participants willingly shared their understanding of dignity and the issues that support or diminish their dignity, and this opportunity to share was observed to be therapeutic for participants. For non-English first language participants, the word ‘dignity’ had to be expanded on by isiZulu terms that meant self-worth, self-esteem and self-confidence. On understanding its meaning, participants shared significant insights. Participants described dignity by internal states of mind such as pride, respect, esteem, self-worth. They stated that dignity is also affected by external components such as illness and displays of attitudes and behaviours from others based on others perception of one’s worthiness, and dignity was described as being “very vulnerable to outside attack.” Specific detailed emotive experiences were recounted where their dignity was diminished or supported.

Those with a strong sense of independence struggled to accept their loss of capacity and symptom burden. The lack of basic security like food, shelter, money and medical assistance was a unique theme that impacted dignity amongst the lower socio-economic group in this South African study versus studies done internationally in Western countries, where social security is not as great a challenge. An overriding theme mentioned by all the participants was the impact the attitude, behaviour and treatment of family, community and healthcare providers had on their dignity experience. In the face of impending death, whilst having numerous anxieties, many shared the attitudes, qualities, perspectives and practices they held onto that gave their life a sense of dignity and meaning which are

outlined below. Psychological and predominantly spiritual coping mechanisms dominated most interviews in this resilient South African population, illustrating a profound spirituality amongst South Africans.

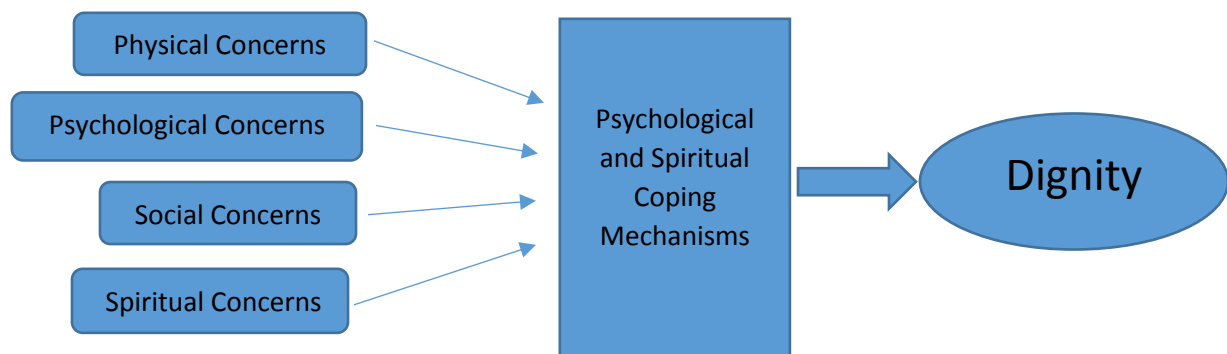
The participants engaged fully in the Dignity Therapy and Guided Imagery, illustrating the acceptability and relevance of this bundled intervention for South African patients with advanced disease. This study provided quantitative and qualitative data illustrating the impact of Dignity Therapy and Guided Imagery, which proved to enhance the intrinsic and extrinsic dignity experience of patients with advanced disease.

All patients enthusiastically engaged in the interventions except one participant who needed time to debrief prior to full engagement. This participant was psychologically distressed from rejection and lack of support from his family. It was difficult to engage in creating a legacy document when basic needs like food, money, medical needs and shelter were minimal and being threatened. A lot of time was spent to allow him to share his worries and concerns, which was therapeutic in itself, prior to engaging in the intervention. However, he felt psychological relief in having the opportunity to share his concerns and disappointments. On engaging in the interventions, he was very appreciative of the legacy document and shared, “I will keep it at my bedside and read it to myself again and again, to remind myself of my good life.”

Another participant appreciated the non-threatening nature of the bundled intervention: “The way you handled it; you don’t force things onto people and they can think for themselves; what they want to say and what they want to do.”

6.2 Model of Influences on the Total Dignity Experience of a Patient with Advanced Disease

The sum total of each one's dignity experience was observed to be based on the assaults to an individual's dignity by an individual's physical, psycho-social and spiritual concerns, buffered by the specific individual's positive psychological and spiritual coping mechanisms.



This model suggests that an individual with under-developed psychological and spiritual coping mechanisms will suffer greater assaults to their dignity. Those patients who had strong psycho-existential coping mechanisms seemed more immune to the assaults on their dignity by bio-psycho-social-existential concerns. However, if the assaults by these concerns were large enough, this can override psycho-existential coping mechanisms and have a deleterious effect on dignity. Thus, this model proposes that to improve dignity experience in the dying, psycho-existential coping mechanisms need to be encouraged and bio-psycho-social-existential concerns need to be allayed in the total care of the patient.

6.3 Four Domains (Bio-Psycho-Social-Spiritual) Influence the Total Dignity Experience Amongst Patients with Advanced Disease

From the interviews, for each patient there were two or more unique overriding themes that dominated their personal dignity experience, and collectively these contributed to the four domains that shaped the total dignity experience of patients with advanced disease.

A. Physical Domain

Illness Related Factors: For the participants who based their worth on their ability to be “productive” or “a man”, physical concerns became the dominant theme cascading through their interviews. This study supported previous studies which illustrated the importance of level of independence on retaining dignity (44,58,64). A loss of independence was described as “disgusting”, “this is breaking my heart” and “it is the worst thing in the world for me!” In some cases, this was such an overpowering theme in highly independent individuals that nothing could support their dignity unless their illness or symptomatology improved. As noted by Chochinov et al (43), the impact of personal character (neuroticism) could also be harmful as in the example of a participant who described himself as extremely fastidious. It is this unyielding, inflexible personal character trait that contributed to his lack of acceptance and exacerbated his experience of dignity with his loss of functional capacity in advanced disease. As noted in previous studies (44,64), being incontinent and dependent on others for toileting and ablutions was a source of great distress in these individuals. Those who had lost their independence felt hopeless and expressed a wish to die. Acceptance was difficult and suffering severe. As Chochinov stated, to feel who you are is being threatened and that you are no longer the person you once were, can cause distress to body, mind and soul (38). Yet, those who had very active and productive lives but challenging life circumstances over a long period of time and thus greater resilience and better existential coping mechanisms, accepted the loss of functional capacity.

Symptom burden, especially that of pain, was debilitating and a source of grave suffering and provoked thoughts of wishing to die as documented in a study by Krakauer (32). A determined, resilient individual expressed a wish to die because he could not cope with his poorly treated pain. However, his pain was exacerbated by his psychological distress from loss of function and existential dilemmas of wanting to die because of loss of role. His feelings of wanting to die was lessened as he engaged in the dignity enhancing interventions and his life felt more meaningful, purposeful and feelings of suffering was lessened. He shared that he felt less isolated and was encouraged to “confront his shortcomings and do something. I must help myself more.”

Thus, supporting these patients with better psycho-existential coping mechanisms that enhance a sense of self, their intrinsic worth, is important. When physical systems of the body are failing, patients can benefit from the stability and permanence derived from an affirmation of their nonphysical identity. As Brennan stated, patients need to be reminded that nothing can take away their spirit, *who they are*, not even serious illness (19). With this understanding, there may be physical pain but not suffering from the psycho-existential pain associated with a loss of identity. Furthermore, as Krakauer suggested (32) advocating for better pain relief and education of healthcare professionals in the use of analgesia will better support patients debilitated by pain.

Lack of Basic Human Needs: Basic Security was a governing theme in this South African study in the lower socioeconomic group versus international studies in developed countries, where social security is well developed. The basic human needs of food, shelter, money and medical assistance (which include transport/ access to care, access to medication and continuity of care) were scarce and threatened, and impacted harshly on patients' self-perception of their value and worth as individuals. Loss of functional capacity and role meant loss of income and food for a family. This affected a mother in a single parent household so severely that she expressed a wish to die because of her inability to provide for her family. People live in cramped conditions or makeshift homes that are not conducive to best care. Many families live on an inadequate pensioner's and disabled person's social grant. Children become sources of support. With a lack of basic human needs and rights, life seems hopeless and has no meaning or purpose. In addition, not all people may have the financial support and information on how to proceed to acquire identity documents, and thus they may not be able to acquire a social grant at this time of desperate financial need. Lack of finances also affects continuity of care in the public sector, because patients are unable to keep their appointments if they don't have the finances for transport. This delays diagnosis and treatment and patients feel devalued and this worsens their experience of suffering. If a patient is wheelchair bound, they struggle to get to hospitals because there is no transport, occasionally spending an entire month's grant on a single trip to the hospital, sparing no funds for a repeat visit to the hospital in a single month. Occasionally, medicines are unavailable in the public

healthcare sector thus symptomatology is untreated and this burden creates a greater experience of suffering.

To provide holistic care that supports the dignity of patients nearing death, these basic human rights need to be addressed at a national level and social workers need to be involved as part of a multidisciplinary team to ensure these basic needs are met. As per Maslow's hierarchy of needs, these basic physiological and safety needs precede need for esteem, and self-actualisation (97).

Treatment by Healthcare System: In South Africa, where the public health care system is overburdened (54,55), consultation time is short, with long waiting periods to diagnostic tests and specialist consultation at separate facilities and no continuity of care in terms of consulting the same physician. Thus, diagnoses are delayed. Financial difficulties for travel to healthcare facilities also prevent patients from lower socioeconomic groups from keeping their appointments, which further delays management of disease. Short consultation time and poor communication skills and information sharing with patients by healthcare providers also leaves patients feeling frustrated. Participants felt that healthcare providers were time-bound and did not understand the patient and their needs. This led to patients feeling hopeless, dissatisfied and frustrated with medical care. They felt disrespected by the attitudes and behaviours expressed by healthcare providers in the treatment they received in their vulnerable state. This worsened their suffering and undermined their dignity. However, a participant who attended the private healthcare system equally described how he felt "totally undermined by his physician" when his pain was mocked publicly, dismissed and his right to basic pain relief was not met, due to lack of knowledge on adequate pain management. Short consultation time, poor communication skills and disrespectful attitudes and behaviours of healthcare providers left the patients feeling unsupported, undervalued and hopeless.

Publication and presentation of the study findings may sensitise healthcare providers to the difficulties and vulnerabilities experienced by patients who seek their care. They may become aware of the impact of their attitudes and behaviours on the dignity of patients. Patients need to be seen for who they are with their unique challenges and vulnerabilities.

When they are seen, and acknowledged as living beings rather than objects needing fixing, this is the first and most important step in a therapeutic relationship. This simple attitudinal change does not require time or skill, but a willingness and constant attention to know and care for the whole person rather than just to treat the disease. We have operated for too long in a system that has emphasized the biomedical model of care (6,50). However, in an overburdened system all are challenged, patient and healthcare provider alike. Healthcare providers also need to be supported by continuous professional training and awareness of a more productive system that addresses the whole being, that includes better skills in communication and awareness of patients' sources of distress. Healthcare providers themselves need care and support to function optimally in mutually stressful environments, where emotions of both, patient and healthcare provider, are high.

B. Psychological Domain

Fears and Anxieties: Participants expressed numerous anxieties and fears that arose with advancing disease that adversely affected their dignity experience. This related to fears of loss of functional and cognitive capacity and their ensuing dependency on others as noted in other studies (44,58,64). Fears of loss of role and particularly being a burden on others as noted in other studies (42,43,49) were cause for distress and impacted on their perception of their value and worth as individuals. Added fears included:

Vitality: A source of immense suffering was a loss of vitality. As per Metz, vitality is an important concept in the African conception of dignity (94), which is grounded in community and vitality. Vitality refers to the inherent life force which is a valuable, spiritual and invisible energy within physical things, and man possesses a greater share of it than inanimate objects. It also refers to a liveliness and creative power within man. Every illness, all suffering, fatigue or depression results in a diminution of this vital force. Vitality and external appearances of wellbeing seems to be an important factor amongst the African population, thus one would propose the use of appetite enhancers to attenuate the symptom of cachexia in the care of African participants with advanced disease to enhance the experience of dignity. However, the use of appetite stimulants has been found to be controversial. Dietary modification, nutritional support, exercise, close clinical

evaluation and management of diseases (that can cause weight loss) is supportive to delay weight loss. In addition, prevention of treatment-related nausea, vomiting, diarrhoea and dysphagia is important. Management of depression will also help alleviate anorexia. However, when cachexia is irreversible, patients need to be counselled to understand that despite their physical decline, their spirit, their true life force can still be radiant and unaffected. An experience of intrinsic dignity will support this.

Body Image: The concept of body image, which refers to a self-perception of one's own appearance or attractiveness in relation to others or cultural norms, did arise in interviews as a concept that erodes one's dignity, in keeping with other studies (44,60). A participant who suffered because of his loss of mobility, refused to use a walker thereby hampering his mobility and medical progress, because he did not perceive himself as dignified using a walker. Interestingly, body image was found to be insignificant amongst two young patients possibly because they had strong psycho-existential coping mechanisms and good social support structures. Both individuals were very introspective, and reflected and processed their experiences - their emphasis was on who they were, not what their bodies had become. This illustrates the benefits of affirming intrinsic dignity on body image.

Fear of Abandonment and Abuse: Participants also expressed considerable distress due to fear of being abandoned by healthcare providers and being abused and disrespected by family and community in their vulnerability (by having their property, possessions, money and choice of residence taken away). Abuse is possible in the townships areas of South Africa where land is not owned but belongs to the people who are themselves in desperate need of basic security with poverty and lack of resources, as noted in a study conducted in the Eastern Cape (96). This was a source of deep sorrow taken from loved ones in this study. One would expect support and comfort and compassionate care in their vulnerable state of health.

Some of these fears may be realistic and others anticipated as noted by De Lima (29) but they are real to the patient and need to be allayed. In providing dignity conserving care as expanded on by Chochinov (21), healthcare providers including hospice staff can offer compassionate listening to acknowledge and begin to understand these potential

anxieties in all patients, whose entire world view has been shaken. They can offer reassurance and assist the patient to explore their own resources to find solutions to alleviate the distress associated with their fears. Often just being present to listen to one's fears and anxieties is therapeutic in itself for the patient. This study provides an understanding of some of the anxieties to consider in a therapeutic relationship that aims to support the whole person.

Psychological Coping Mechanisms: As noted by Chochinov et al in the Dignity model, there are many dignity conserving strategies (10) employed by patients to preserve their experience of dignity. It was observed that those who had more challenging lives and greater assaults to their dignity over a longer period of time, had greater resilience in overcoming adversity and this had a positive impact on their dignity in disease and dying. Autonomy in the home and in medical care improved one's sense of control and dignity. Living one day at a time was a common coping strategy used by patients so that they would not become overwhelmed with worry about the future. Knowing that in their passing, they will leave something of benefit to others (legacy) brought comfort and meaning to participants lives. Role preservation, even in little ways, was found to bolster dignity. With this awareness of the above mechanisms that support patients' dignity, healthcare providers can promote these practices.

C. Social Domain

Social concerns were a prevailing theme for many of the participants in this South African study and the cause for tremendous grief. There was a grave impact on an individual's dignity from unfulfilled expectations of social support.

Community as an African Conception of Dignity: As stated by Metz (94), community is an important consideration of personal dignity in an African context. A conception of dignity in Africa is that our communal nature makes us most important beings in the world. **Ubuntu** as a code of ethics in African communities (95) seeks to honor the dignity of each person and is concerned about the development and maintenance of mutually affirming and enhancing relationships. Ubuntu is the capacity to express compassion, respect,

harmony and humanity in the interests of creating and sustaining community with justice and mutual caring.

Social Support: In view of the principles of Ubuntu, the powerfully deleterious effect of lack of support structures on dignity amongst the African participants in peri-urban townships was very evident. One participant cried throughout his entire interview because he was rejected and treated with disrespect by his family and community despite having provided all his life for both, supporting the community by opening a crèche for children so that women could go to work. Instead of providing support and care, the family and community rejects him and attempts to steal his property and belongings. The distress protocol had to be invoked in this case but the participant wished to continue with the interview as it gave him an opportunity to be heard. Another participant resigned herself to never having social support. She declared that God was her only support. Participants shared deep sorrow and suffering from a lack of family and community support. They were ostracised and felt that they were a burden to society. Interestingly in this study a feeling of burden on others correlated with the psychosocial distress they experienced, rather than their actual physical dependence on others, as noted in Chochinov et al's study (43). Participants were hurt and expressed a wish to die as a result of a feeling of isolation and lack of worth.

From the interviews, the reasons given for the erosion of community support was poverty, crime, alcoholism, drug addiction and decline in morals, values and motivation amongst the younger generations in townships. Jealousy and corruption were also alluded to. Stigmatisation had replaced community support in all four participants from the African cultural backgrounds living in townships. These factors were also expressed in a study in the Eastern Cape to explain the erosion of African communal values with urbanization and development of overcrowded peri-urban townships (96). The immense psychological distress experienced by African participants in this study from a lack of social support, compassionate care and respect was very disabling to human dignity. However, the same study (96) suggests that the values of Ubuntu, if consciously harnessed, can play a major unifying role in the process of harmonising the South African nation. Seeking comfort in personal spiritual practices or from religious organisations or places of worship, and

acceptance were predominant psycho-existential coping mechanisms that were employed to compensate for this lack of community support. Resilience was unyielding and commendable.

Nevertheless, the role of good support structures in boosting dignity was observed in other socioeconomic groups. It was also found that to continue to live and support their children was also the source of inner strength and willpower for women from all cultural backgrounds in this study. However, it was noted in this study that highly independent individuals who chose to live isolated from their family struggled with lack of social support, but were reluctant to seek the help of paid staff and felt that they were a burden to neighbours in desperate circumstances. This illustrates the impact of personality trait on the experience of dignity, suggesting as Chochinov said, that “who we are” has an influence on “how we die” (43). Internationally there are studies illustrating the benefits of building compassionate community networks that support the dying (33-35). Hospices in South Africa provide this care, but this shift in consciousness to become compassionate communities can be considered by community members in South Africa. Places of worship are increasingly seen to provide compassionate community networks in South Africa.

Compassionate Care and Respect from Family, Community and Healthcare Providers: Participants expressed their appreciation for the attitude, professional behavior, valuable dialogue and compassionate care expressed by their healthcare providers. This complements the literature on Dignity Conserving Care by Chochinov (38). Professional, compassionate care provided by respectful healthcare providers with good communication skills supported the dignity of patients when they were exposed to circumstances that would potentially have a deleterious impact on their dignity. The hospice staff provided compassionate supportive care with assistive devices, nursing care, dietary advice and a therapeutic presence.

As mentioned by numerous studies on dignity (38,44,45), experience of patients' dignity was very dependent on how people treated or respected them. Many felt disrespected and adversely affected by others treatment of them in terms of the attitude, behaviour or words used. One patient described this as, “...your sense of worth is also affected by how

other people treat you... it certainly is deep inside but very vulnerable to outside attack.” Being disrespected was a source of psycho-existential pain and suffering. Being disrespected was described as impacting negatively on one’s physical health, “whilst if one was treated with respect, one’s health improved.” Awareness of the dignity experience of the dying by studies such as this, will inform healthcare providers, family and society and assist them to respond more sensitively with compassionate respectful care to this vulnerable population.

Stigma: Stigmatisation by family and community was also an added theme not mentioned in the Western studies. It is apparent from this study that stigma toward HIV is still very much prevalent. Despite two participants being ardent communicators for the education of AIDs in their communities, they suffered assaults to their dignity from gross stigmatization by family and community. People refused to use the toilets that they used, use the utensils or eat the food they touched nor wear the clothes they wore and insulted and blamed them for their HIV infection. National campaigns need to be intensified to address stigma in HIV/AIDS. Stigma in the Indian population with regard to life-threatening illness was also mentioned in this study, where the disease is kept a secret and the patient isolates them self from society for fear of stigmatisation. However, participants shared that there has been an improvement in this stigma as cancer is becoming more prevalent in the population.

Burden to Others: Feelings of being a burden on others as in many international studies (41-44) also correlated with depression and hopelessness amongst participants. This feeling was expressed by those who had lost their functional capacity but more so by those who experienced psychosocial distress. It can be exacerbated by family turmoil that can be experienced with the diagnosis of a life-threatening illness. As described by Chochinov et al (43), those who feel that their life no longer has value, meaning and purpose (self-deprecation) will project these feelings onto others. They feel that in having to take when they have nothing to give, they are a burden to others. Often if patients are encouraged to speak about their feelings to their family, they will feel less isolated and be able to appreciate that their family members wish they could do more, and are struggling with similar concerns. Family meetings can be facilitated that allow these conversations.

As Giles Fraser said, “I do want to be a burden on my loved ones just as I want them to be a burden on me – it's called looking after each other. For it is when we are this vulnerable, that we have little choice but to allow ourselves to be loved and looked after.”³

Shame, humiliation and suffering is experienced when privacy boundaries were impacted on for the first time and privacy is a significant aspect to consider when providing dignity preserving care, as noted in numerous studies on dignity (10,22,44,57). For one participant whose privacy boundaries were challenged but who had the support of good communication and kind, respectful and compassionate healthcare providers who took the necessary steps to minimize threatening her dignity, challenging her privacy boundaries had minimal impact on her.

D. Spiritual Domain

Seeking spiritual support from personal spiritual practices or from organized religion and places of worship and turning to God was a principal theme in this study, whilst being one of the factors influencing dignity in other studies (10,22,44), thus illustrating the colossal role of spirituality amongst the South African people in preserving dignity.

Support from Organised Religion and Places of Worship: In this study faith and trust in God and prayer was a source of great strength. Support from places and congregations of worship was an important source of support amongst most patients. Those who had a strong spiritual or religious affiliation seemed to have stronger coping mechanisms as discussed by Cole in her study (90). If a patient had a strong religious or spiritual foundation, the deleterious effects of loss of role and independence would be buffered by their spirituality even if their entire life and identity depended on their physical strength and capabilities. Spirituality assisted patients in being less reliant on their physical ability for their self-worth. This suggests that patients should be referred to chaplains and religious/spiritual leaders and supported to participate in religious/spiritual/cultural based practices that can help patients bring strength, closure and peace of mind.

Support from Personal Spiritual Practices: Participants also mentioned the personal spiritual practices used to find meaning in their challenging life's experiences. These practices need to be encouraged and supported in patients to maintain their dignity.

- 1. Affirming Intrinsic Worth:** Participants acknowledged and affirmed an intrinsic worth that is “deep inside”, that could not be taken away from them, as sanctioned in 1948 by the Universal Declaration of Human Rights Article 1 (17). A participant described the concept of free choice in how she experienced life, rather than allowing situations or people to have power over her feelings. Even those exposed to the worst physical and social circumstances affirmed that “no one can take it (dignity) away” from them. “You always think of yourself as a somebody, not a nothing!” In this South African study, there appeared to be a recognition amongst the participants that dignity belongs to each individual, a recognition of their unique inherent, unconditional, intrinsic worth as described by Sulmasy (20) and Brennan (19). The participants seemed to hold this understanding and deep self-awareness of their human dignity. In a country that has undergone a transition from apartheid where the people were deprived of their dignity and rights, resilient South Africans have developed a recognition of their importance as individuals who have rights, dignity and personal worth. In Western studies, there is a recognition of personal worth in being dignified social beings that deserve respect through interaction in social settings as autonomous persons. This dignity must be earned and can be lost as described by Jacobson (18). But in this South African study there is a deep recognition amongst individuals of their unique worth as living beings, who are worthy because they exist.
- 2. Maintaining Hope:** As described in Chochinov’s studies (8,10), maintaining hope is another spiritual practice that supports dignity. A hopefulness was described that defied doctors and prognosis, a confidence participants held in themselves despite their challenges, and a hopefulness to continue to serve others who were in worse circumstances, and it was born when one found meaning in the challenge as described by Chochinov (10). Hope was shown to ignite a strength and perseverance of spirit that defies physical norms.
- 3. Acceptance and Letting Go:** Acceptance and letting go were observed to be prime in those who have a strong religious or spiritual base. Acceptance is a

concept that is associated with a 'good death', as noted in different studies (8,10,22). In this study, it was also seen to be a practice that comes with maturity, patience, and time along the disease trajectory. Letting go was associated with a feeling of liberation from the entanglement of everything tangible that they had attempted to control that had gripped their spirit. A study by Cole (90), also found that letting go through spiritual practices is helpful in coping with things beyond personal control. One participant described the struggle, suffering and stress of holding onto expectations as damaging to her health, thus she practices acceptance and letting go. A study by Eremin, which showed the positive impact of Relaxation Therapy and Guided Imagery on immunomodulation (104) among cancer patients, confirms this patient's assumption.

4. **Gratitude:** Many participants referred to the dignity preserving perspective of gratitude and appreciation to support their personal dignity, a theme not mentioned in international studies. This perspective had a powerful positive impact on their dignity. Gratitude and appreciation for what they had, helped them find meaning and gave these individuals an experience of being greater than their circumstance.

6.4 South African Versus Western Model of Dignity – Cultural Differences and Challenges

The themes emerging from this research study supported the Dignity Model described by Chochinov et al (10) with the inclusion of additional themes of frustration and dissatisfaction with medical care, basic security, vitality, stigma and gratitude. In this study, physical concerns related to the illness were minimal and were overcome provided there were strong social support and psycho-existential coping mechanisms. However, basic security, a theme not mentioned in the Dignity Model became an important concern especially for those from lower socio-economic backgrounds. Whilst there were several psychological fears and stressors, the sample population in this study illustrated a resilient South African population, who employed various psychological and spiritual coping strategies to preserve their dignity. Social concerns were also an overriding theme with emphasis on social support, respect, compassionate care and stigma influencing the

experience of dignity in the majority of the participants. The spiritual domain played the foremost role in supporting the dignity of resilient South Africans.

Amongst the four African participants in this study, due to the importance given to community and vitality in the experience of dignity in Africa, the lack of social support, respect and stigmatization in the townships were highlighted. Thus, a cultural domain should be added to the model of dignity in this South African study as culture had an influential impact on dignity. Children became the support for mothers in single-headed households in the townships, where there is no spousal support. Basic amenities were sparse and threatened. Despite these enormous challenges, their spirituality was their pillar of strength.

Amongst the four white participants, a sense of independence was very strong as noted in Western Studies – functional capacity and cognitive acuity was vital. If this was challenged, a wish to die was expressed. This strong sense of independence leads to social isolation thus limiting social support. This sense of independence can be so strong that even in the final stages, one will not accept a home-based caregiver, despite having more than adequate financial means to support it. Another participant illustrated how one can punish oneself for being physically incapable despite having loving, supportive and available family. One would wish to die rather than be a burden to loved ones.

Amongst the Indian participants, good social support structures and spirituality were dominant themes. Stigma related to life-threatening illness was noted but was thought by participants in this study to be decreasing in current day.

These cultural differences cannot be assumed to be extrapolated to represent an entire cultural population because within each culture, individuals' socialization may be quite varied - experiences are highly individualistic and not necessarily culture-bound.

6.5 Benefits of Dignity Therapy and Guided Imagery on Four Domains of Dignity Experience

In selecting a study sample of participants from diverse ages, genders, races, socioeconomic classes and cultural and religious affiliations, diverse life-threatening diseases, stages of illness and levels of distress, a balanced comprehensive platform is provided in this study to obtain an overall assessment of the benefits of this bundled psychotherapeutic interventions. In addressing the psychological and existential suffering experienced by patients towards the end of life, there are very few non-pharmacological interventions (11,82,92). The beneficial impact of Dignity Therapy and Guided Imagery on the dignity experience of dying patients was quantitatively documented with confirmations on measures of helpfulness, satisfaction, a heightened sense of dignity, purpose and meaning in life. Further endorsements were expressed in terms of lessened sense of suffering, lessened feelings of anxiety and depression and improved will to live. The participants also expressed that the beneficial impact of interventions would spread beyond themselves to help their families and to benefit their relationship with their healthcare providers. It was noted that the interventions in this study supported the dignity experience of patients in the four domains as evidenced by our qualitative findings above.

A. Physical Domain:

Dignity Therapy and Guided Imagery supported an experience of physical healing, muscle relaxation and greater strength. This study confirmed findings in another study by Tusek (102), whereby the experience of pain was improved with Guided Imagery.

B. Psychological Domain:

As noted in other studies of interventions aimed to relieve psycho-existential distress (37,99,100), Dignity Therapy and Guided Imagery enhanced dignity and purpose. Having the opportunity to share their feelings, emotions, achievements and contributions and choices in life was therapeutic and allowed the patient to feel understood, respected and valued as a person, rather than a disease. As stated by Chochinov, affirming personhood is important (21). It also offered them an opportunity to feel that they were being heard, which was therapeutic in itself. Suffering was lessened as they accepted, let go by detaching from their immediate challenge and thought broader by reflecting, learning and finding meaning and purpose in situations. This confirmed that Dignity Therapy and Guided Imagery can complement meaning-focused therapeutic interventions shown in

studies (90,92) to enhance dignity in the dying. As noted in studies on Dignity Therapy (37,77), participants felt more positive, hopeful and less depressed after the interventions. They were also reminded that they did possess the strength to overcome and can do so once again. Participants who had felt restless with the fears of death felt more calm and relieved from pent-up anxiety, which confirmed studies that illustrated better comfort levels with Guided Imagery (99,101) . Participants described having greater clarity, acceptance and less anxiety, isolation, fear and frustration.

C. Social Domain:

Dignity Therapy and Guided Imagery was found by patients to relieve suffering experienced from social concerns and to potentially improve relationships with their family in terms of: 1) Sensitizing the family to understand ‘who the patient is’ and their journey of emotions so that the family can be inspired and can offer greater support and respectful compassionate care, rather than stigmatise patients; 2) Sharing of life’s lessons and good wishes for the family by affirming the patients’ love, advice and principles for living; 3) Being less self-absorbed and positive, patients can have better relationships with family and the family will be less stressed by the patient’s distress. This study confirmed a study by McClement et al (66), which illustrated the benefit of Dignity Therapy on the family unit. Ninety-two percent of the patients shared that their relationship with the Health Care Providers (HCPs) will improve. Reasons given were that if they have greater self-confidence and a higher vision of themselves, the HCPs will reciprocate in their vision, HCPs will also have greater respect because they will understand patients and their needs and sensitivities better and HCPs will be encouraged to perform better if their patient are “happier and doing better”. One participant described it as “a two-way thing”. Thus, as mentioned by Sulmasy (52) and Chochinov (21) these interventions protect the wellbeing of patients and HCPs alike.

D. Spiritual Domain:

The ultimate benefit gained from the interventions was found to be alterations to their sense of self-esteem and worth. Life was described as “more meaningful” and purposeful. The Guided Imagery brought self-awareness and gave participants an opportunity to reflect and reassess their identity: “Who I am?”. Identity was found to be one of the

existential concerns patients with cancer wrestle with in a study by Cole (90). Self-awareness brought relief, a positive attitude and acceptance as they recognized that as living beings they were worth more than their disease and body. It created a feeling of security in the experience of the living beings that they are, that made them feel “lighter, purer and less worried about the things outside of themselves”. The study confirmed a paper by Chochinov on dignity conserving care whereby participants spoke of the importance of consideration of the soul (38) and the interventions reaffirmed for them that it is important to take care of the spiritual aspect of their health. Patients described “being healed from the spirit”, with lessened feelings of wanting to die. It helped to bring a balance of body and soul, after what a participant described as a detachment of soul and body that she had experienced during the intense pain-ridden experiences of chemotherapy.

Hopefulness and a greater will to live was a dominant theme of benefit experienced from the interventions in this study, confirming the benefits of psychotherapeutic interventions on hopefulness in other studies (37,64). The interventions reminded patients of how driven they were in life, how much purpose they had and that they still had purpose and they can still fulfil more tasks on their bucket list and leave a better legacy and “mean things to people” and inspire others. As said by one of the participants, “There is light at the end of the tunnel.” Participants had newfound acceptance after fighting a battle of failed expectations of their bodies, family, community, medical professionals. After the intervention, one described that when he accepted and let go of his frustration at the hospital, “then things opened up.”

6.6 Specific Benefits of the Dignity Therapy and Legacy Document

In keeping with international studies on Dignity Therapy (37,70), being supported to create a legacy document, created a deeper sense of meaning and purpose in the lives of participants, because they could share their life story with others and inspire them. It also served to inspire the participants themselves as a tangible reminder of their worth, strengths and achievements. The legacy document was described as an important tool to build resilience, reduce stigma and be a source of learning for family. Dignity Therapy

helped change how patients viewed themselves and how others viewed patients because it enhanced understanding of and respect for the patient. Thus, the legacy document enhanced extrinsic dignity.

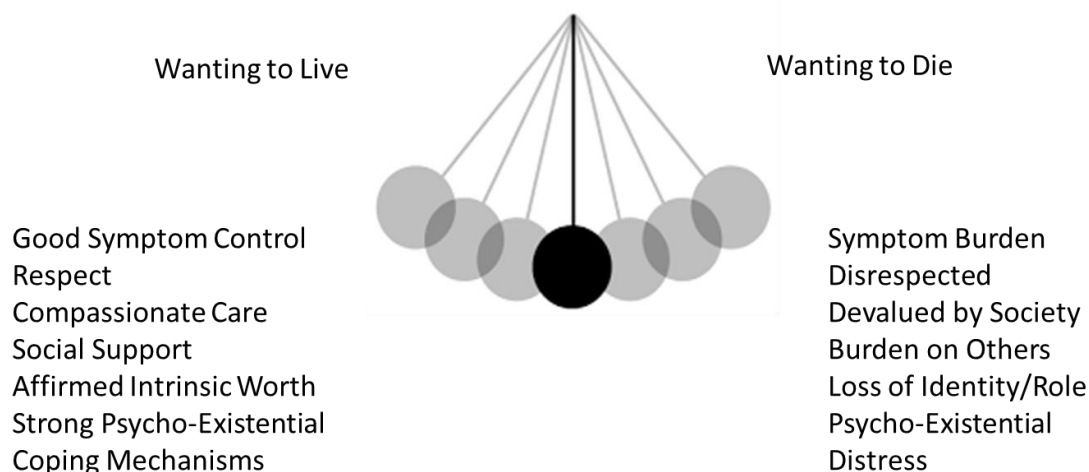
6.7 Specific Benefits of the Guided Imagery

On the other hand, Guided Imagery provided an experience of innate worth thus affirming conviction in intrinsic dignity. All willingly participated in the Guided Imagery, and found it very “acceptable”, “appropriate and useful”, innovative, helpful and “soothing”. It enhanced comfort levels as noted in other studies on Guided Imagery (99,101), by enabling participants to feel more peaceful, less anxious and relaxed because they were able to detach from their circumstances and “put things into perspective.” Most of all, it brought a new-found pride and esteem and deep self-awareness of their identity: “Who I am?” an existential issue very important in building dignity as shown by Cole (90). They felt secure in the experience of being more than their disease and body. “It makes you think...this is who I am...Now you feel freer and the worldly things mean nothing, even the body means nothing, the spirit goes on...the body can die. That is fine. Your spirit goes on...your life.” The Guided Imagery altered thinking and attitudes (more positive) and reduced depression and increased the will to live. This manifested in an observed physical improvement in wellbeing, especially in the case of one patient who barely interacted in the first interview, was bed-bound and whispered his responses. After the intervention, he walked unaided, had a strong, powerful voice and confident interaction. He volunteered that he had realised that he was depressed. Another participant shared how she could not rid herself of suicidal thoughts despite repeatedly seeking counsel from her priest. After the Guided Imagery, she was free from suicidal thoughts, wanted to start a business and started counseling others who wished to die. Having taken benefit, participants felt inspired to share the Guided Imagery with family and congregations.

Two shared that Guided Imagery could be a stand-alone intervention as this is what benefited them most. Two participants specifically requested that the Guided Imagery be recorded so that it can be played at their bedside, as listening is easier than reading. A retired Sergeant Major of the Defense Force described it as “very well done” and

“professional” and gave specific instruction as to how the recording must be done, and a daily programme for the Guided Imagery created to build intrinsic dignity. It was also noted by this participant that the recording can be used at family meetings.

6.8 Pendulum of Wanting to Die / Wanting to Live



In this study and others (24), participants feel safe to recount times in their life when they expressed a fleeting wish to die without acting on it. However, participants expressed that the wish to die is a transient thought when assaults to their dignity are extreme in terms of the aspects of the physical and psychosocial concerns. Yet, retrospectively they would never actually want to act on this wish. Those who had a strong dependence on their functional capacity for their worth, poor social support, or poor symptom control in terms of unmanaged pain (32) expressed a wish to die. Whilst other women living in impoverished circumstances, highly stigmatised and ostracised by society with no basic security rejected this option, but contemplated a wish to die when they felt they were a burden and felt unsupported by family and community. In retrospect participants shared that they were “stupid” to have even considered such a thought. Some shared that they are “too strong” to act on this wish or classed these thoughts as “bad thoughts” that they pushed aside. Whilst others absolutely rejected this notion, choosing to focus on positive things, their religion and their Creator. Another participant with insurmountable physical assaults to her dignity, who had at one time contemplated physician-assisted suicide, stated that she had come to realise that she could still “live with dignity, a dignified life”.

Participants seemed ambivalent about the wish to die and seemed to swing from moment to moment with the pendulum in their wish of wanting to die and wanting to live depending on their experience of dignity from moment to moment which is in keeping with international studies (23,25). Unfortunately, 'dignity in dying' has been used to describe euthanasia, suggesting that people who are ill and dying cannot have dignity. However, from the patients in this study, it can be seen that dignity is a construct that is possible even in illness. Wanting to die is often a transient thought which participants feel safe to express without acting on (24). At other times when they felt cared for, loved, respected, valued, with good symptom control and strong in feelings of self-worth, finding meaning in their situations, they want to live. As in previous studies (8,25), this evidence suggests that wanting to die is a reflection of underlying psychological, physical, and socially mediated distress – wanting to die is a litmus test for providing quality end-of-life care (8).

However, euthanasia takes away the choice when a patient is most vulnerable and at their lowest point in their experience of illness. If on this pendulum of emotions, a patient became overwhelmed and expressed a wish to die and euthanasia was in the process to be executed, vulnerable patients would be robbed of a choice of taking the turn to want to live. As one participant said, "... only one who is in that situation will know what it feels like to be at such a low point. For me when I am at that point, I feel like I am at the bottom and the only way to go is up, so after that it will get better and I feel most of your illness is in your head.... its 99% of your attitude and positivity and the vibes that you give out.... so I try and just ...stay calm." It appears that they may be at a crossroads. With legalization of euthanasia, one small utterance of a wish to die, an ideation not intent, in a moment of weakness, may be fatal forever with no chance of turning back.

6.9 What Does This Study Imply? What have We Learnt? How Can This Be of Use to Patients with Advanced Disease?

How is it that some people with advanced disease can retain their dignity and some cannot? As one of the participants said, "It's not a weakness. Everyone sees it differently and only one who is in the situation will know what it feels like to be at such a low point." How can we learn from those who retained their dignity to help those who lost their dignity? Those who retained their dignity had strong psycho-existential coping

mechanisms. They knew how to accept and let go and had a belief in their intrinsic worth and that nothing can take that away from them, not people and not illness. They sought nontangible spiritual support. In accepting and letting go, they sought to find meaning and purpose in their circumstances. This study showed that Dignity Therapy and Guided Imagery improved the dignity of patients in this study who expressed an increased will to live. It did so by improving attributed dignity and affirming intrinsic dignity. International studies have shown the benefits of Dignity Therapy; this study in addition shows the benefit of Guided Imagery focused on intrinsic worth as an intervention to bolster intrinsic dignity.

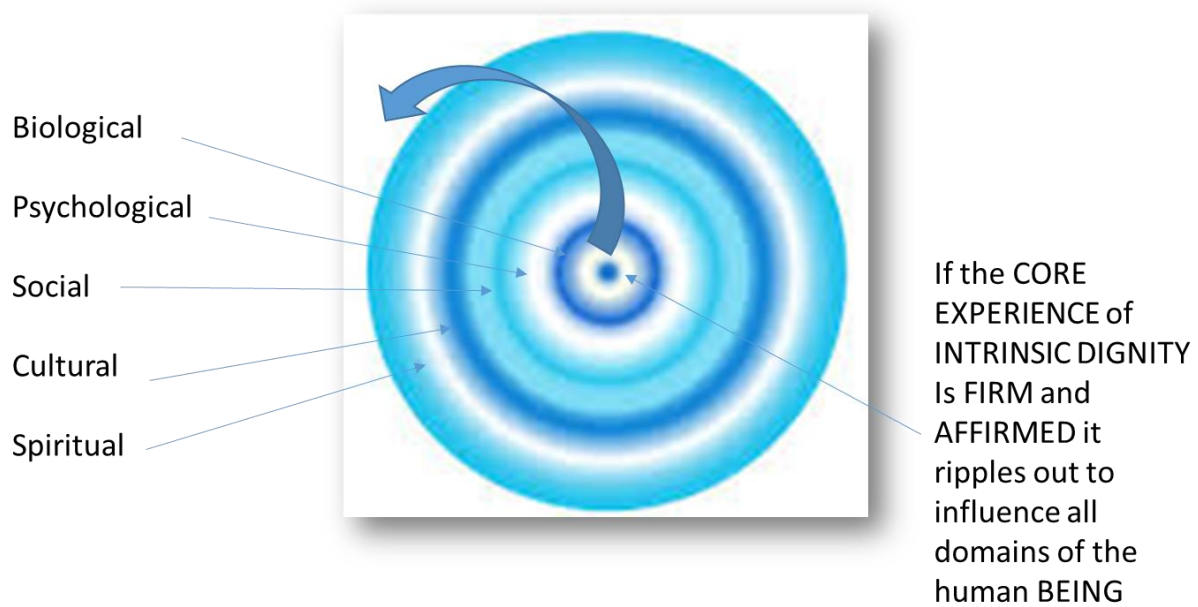
6.10 Dignity Therapy Serves as a Reminder of One's Immortal Worth and Legacy and Guided Imagery Helped Deliver an Experience of the Intangible Intrinsic Dignity

From this study, participants appeared to understand that dignity consists of an untouchable, imperishable, inherent, unconditional, universal component that is present and inalienable, an objective concept that is intrinsic to being human as defined by Brennan (19). However, many noted that it can be influenced by attributed or extrinsic factors - how one sees oneself or how others see you - which is intensely situational. Whilst participants may have theoretical knowledge of the untouchable intrinsic dignity they possess, their practical experience of this falters. Conviction of their innate dignity is challenged when exposed to numerous assaults to their attributed dignity.

As the diagram below illustrates when one is being suffocated by the 'outside attack' of a failing body, distressed mind, corrupted social and cultural systems and when one's existential principles are shaking, one is forced to let go of trying to control, and to turn inwards and recognise one's innate worth and identity, that is powerful, unfailing and yet so subtle. From this study, it was noted that those who accepted and let go of their expectations from horizontal supports, were liberated to lift their consciousness to seek comfort from vertical nontangible spiritual supports. Having forged new relationship with spiritual supports, they then sought to find meaning in their situations and retained their dignity. These findings confirm the four existential issues explored by Cole of control, identity, relationship and meaning (90).

Those who retained their dignity chose not to suffer but to adopt intrinsic dignity as something that originally belongs to them. It is a matter of choice, and as seen by participants in this study this can be done when forced by distress or by free will. Guided Imagery gave patients an experience of their original and eternal dignity. Dignity is the breath of life...if there is no breathe there is no life. Guided Imagery gave them back this breath...patients can be taught to sustain this breath (of intrinsic dignity) with repeated practice, until this breath becomes a natural awareness and experience again. To offer dignity is to give the donation of life to a dying individual. To own the awareness that one is an originally and eternally dignified soul, means to have power and to be free from suffering.

As shown in the diagram, it was observed in this study that if the core experience of one's intrinsic dignity is firm and affirmed and patients have a deep faith that they are intrinsically worthy of esteem irrespective of what their bodies are going through and the psycho-social-cultural and spiritual challenges they may face, this will have a ripple effect on all domains of their life (bio-psycho-social-cultural and spiritual aspects of their life) as confirmed by numerous studies (21,37,66,100,104). This will affect one's awareness, vision (perspective), attitude, thinking, environment, motivation and actions and patients will begin to find meaning and purpose in life's circumstances again. Where there is dignity, there is stability and peace and no suffering remains. So irrespective of treatment by others or bodily illness, people can want to live because their conviction in their intrinsic dignity is deep and cannot be fractured.



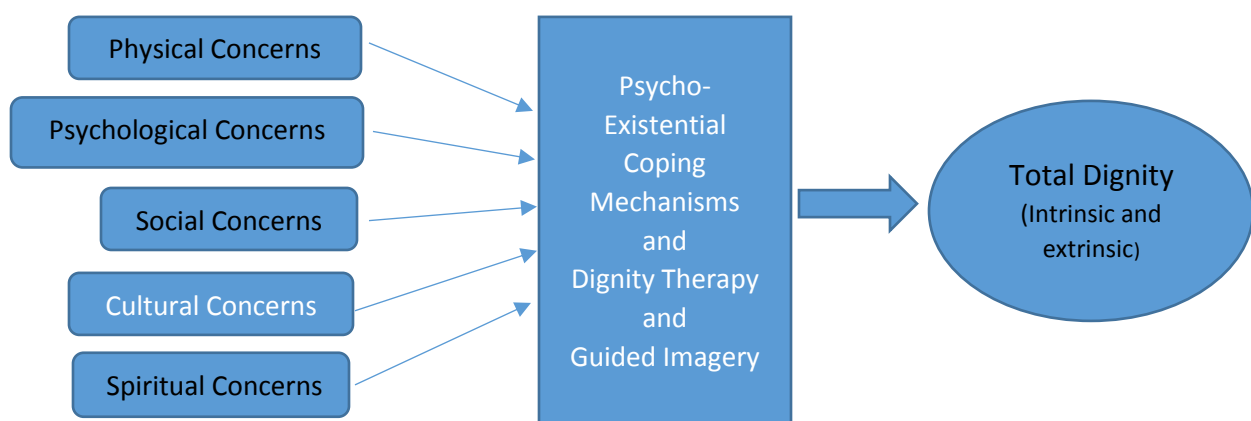
Dignity Therapy and Guided Imagery offers a bundled psychotherapeutic intervention that is feasible to support dignity at the bedside of patients with advanced disease. The structure, tone of delivery and content of Dignity therapy is based on Chochinov's empirically validated model of dignity (10) amongst patients with advanced disease, which

is supported by this South African study. Dignity Therapy serves as a reminder of the immortal worth and legacy of an individual and enhances extrinsic dignity as confirmed by Chochinov (37).

A Guided Imagery focused on affirming intrinsic dignity designed for this study proved to be a relevant, acceptable and practical short 5-minute intervention that delivered an experience of the intangible intrinsic dignity of the individual. It can follow Dignity Therapy, or as some participants suggested, it could be a stand-alone intervention to enhance dignity experience. As described by one patient, "...feeling is important - people may see but not see, hear but not listen." Thus, an experience of their intrinsic worth through Guided Imagery augmented the legacy document to have a beneficial impact on patients' complete dignity. The unique beneficial effects of these interventions lay in their ability to enhance a sense of meaning and purpose whilst affirming a continued sense of worth in a non-challenging, supportive, nurturing environment that is accessible even for those in the terminal phase.

6.11 New Model of Influences on Total Dignity

Considering the findings of this study, the model of influences on dignity proposed above can be modified as below to include the above-mentioned that were explored in this study:



6.12 Limitations of the Study

We recognize limitations of the study. The sample size was only 12. Therefore, despite including an equal mix of ages, genders, races and advanced diseases, whom found the intervention acceptable and relevant and helpful, we cannot generalize the benefits of these intervention with such a small study population, and we will need a larger quantitative study to prove this. The translation of the word “dignity” into isiZulu was difficult. The accuracy of the translated data of the four African patients depended on the translation by the isiZulu-speaking caregiver at the hospice. A home visit by a doctor (the researcher in this study) made participants feel valued and understood by the medical profession and could contribute to bias in the data of this study, because the respect they may have experienced from the HCP may be attributed to the intervention. There was a lack of space and privacy to engage fully in the Guided Imagery at participants’ homes. When necessities are compromised like food, medical needs and shelter, it is difficult to engage fully in Dignity Therapy and Guided Imagery to assess its full benefit.

6.13 Conclusion

The research met the study objectives to understand the personal dignity experience of patients with advanced disease from a South African perspective. The dignity interventions, Dignity Therapy and Guided Imagery was found to be relevant, acceptable and beneficial in enhancing dignity, purpose, meaningfulness, will to live and hope in the lives of patients with advanced disease. It lessened suffering and anxiety and depression, and was found to be beneficial in improving relationships with family and healthcare providers. To add to the knowledge on dignity research, this study specifically highlights the need to affirm intrinsic dignity in dying patients, to affirm their personal untouchable unique worth that belongs to themselves, irrespective of the failing bio-psycho-social-existential systems that surround them. We may never be able to correct these external systems wholly and fully, but we may be able to offer patients a stability and permanence that is attainable (as evidenced by this study) with the intangible experience of their intrinsic worth through the use of a Guided Imagery focused on affirmation of the untouchable spirit.

Palliative care is a basic need. It is a human right to support the universal experience of human dignity which is impacted on by advanced disease. Whilst dignity is an intrinsic, unconditional quality of human worth, it was found in this study to be affected by bio-psycho-social-cultural and existential concerns. South African people have various challenges that impact on their experience of dignity based on their personality and socio-economic backgrounds. In the lower socioeconomic populations, the experience of dignity in advanced disease is severely affected by a lack of basic security, failing social support and lack of respectful, compassionate care from family, community and healthcare providers. However, South Africans are an extremely resilient population who employ several psycho-existential coping mechanisms. Despite the numerous assaults to their dignity, this study has shown that South African people recognise an intrinsic unconditional worth as belonging to the individual, that cannot be destroyed or taken away from them. They recognise their importance as individuals who have rights, dignity and personal worth.

The dignity of an individual is not based on one moment in time in a person's life when challenges in the domains of life (bio-psycho-social-cultural-spiritual) are at an extreme while facing death but is based on unconditional human worth. Dignity Conserving Care involves acknowledging and honouring the being of each one, their identity, value and worth beyond the labels placed on them by their body, bodily illness and challenging connections. It is not about *what they have become but who they are*. The spirit is imperishable and untouchable, and patients need to 1. Be reminded and trust in their untouchable, intrinsic, unique worth as beings and their qualities and strengths, 2. Be reminded to seek and find and trust in intangible spiritual support and 3. Be supported to trust that the process is beneficial and to grow with it by finding meaning and purpose in life's challenging circumstances. These subtle concepts were shown to create a feeling of safety, security and a sense of spiritual peace and wellbeing amongst the participants of this study.

With severe assaults to their attributed dignity because of advancing disease, even a resilient population can forget their intrinsic worth. Intrinsic dignity is an invisible, intangible, subtle concept that can elude an individual. It is easier to demand and expect

support from tangible, physical support structures rather than seek for subtle spiritual support. With extreme challenges, it is not easy to find meaning and subtle benefit in life's circumstances. Yet this study has shown that those who did trust and apply themselves to these subtle concepts retained their dignity under the most difficult circumstances when everything tangible was taken away from them and all they were left with was their untouchable worth.

Whilst healthcare professionals have a greater influence in the area of the extrinsic sources of dignity in advanced disease, it is essential that healthcare providers offer kindness, compassion, unconditional love and respect that acknowledges and honours the being of each one. Patients need to be seen as living beings not disease entities that need fixing, and they need to be supported to create meaning and purpose in their last days. In this small study, Dignity Therapy and Guided Imagery are shown to be relevant, feasible and acceptable, short psychotherapeutic interventions that can be conducted at the bedside by healthcare providers to enhance the extrinsic and intrinsic dignity respectively amongst patients. A Guided Imagery focused on creating an experience of intrinsic dignity is shown to be a beneficial 5-minute intervention that can augment Dignity Therapy, or be used on its own, to affirm and strengthen the experience of the intrinsic worth of patients with advanced disease.

6.14 Recommendations

The themes and subthemes identified in this study provides direction and invites clinicians to consider possible therapeutic options that can preserve the dignity of and care for patients nearing death in a South African population.

Physical concerns related to illness emphasize the need for frequent assessment and attentive treatment of illness concerns through holistic interdisciplinary management and accurate, clear information sharing and communication skills. Basic security needs to be addressed by involvement of social workers and by advocacy at a national level. An added theme that emerged from the African population was the need to address the distress that arises from loss of vitality and cachexia. Dietary advice, nutritional support, exercise, and careful clinical management of gastrointestinal diseases and side effects of

medication will support patients with cachexic syndromes. However, when cachexia is irreversible, patients need to be counselled and made to understand that despite their physical decline, their spirit, their life force is still radiant and unaffected.

Psychological distress needs to be supported through empathic listening and referral for counselling. Patients need to be encouraged in the psychological coping strategies used to overcome adversity and involved in the decision making regarding both medical and personal issues. Patients should be encouraged to participate in normal routines, be involved in momentary distractions and in usual roles to the extent that they can. HCPs should acknowledge and show interest in the aspects of the patient's life that patients most value.

Social workers can assist in broadening the social support network, with involvement of hospice home-based care. At a national level, awareness campaigns can be advocated that destigmatize HIV and life-threatening illness, so that society can be aware of the vulnerability of patients at this time and the respectful compassionate care that is required. Compassionate community networks should be encouraged nationally. Encourage discussion about concerns with relevant parties that the patient fears they are burdening and assist practically where possible with aftermath concerns i.e. advanced care directives, wills, funeral planning. Respect the privacy of patients and ask permission to examine a patient.

Understand the pain behind the expression of a wish to die and facilitate comfort care to alleviate this wish. Connect patients with **spiritual** organisations and leaders and enable the patient to participate in specific cultural and spiritual based practices. Most importantly, see the patient as an individual worthy of respect, honour and esteem, supporting their spiritual stance on life and encouraging and enabling the participant to participate in meaningful activities that enhance their sense of wellbeing.

Three participants suggested that the **Guided Imagery** should be available on CD so that it can be a tool to assist them to re-experience their intrinsic dignity at will. It was

suggested that it be developed, made longer, and be “read by someone with a soothing voice with feeling”, “maybe a few different ones on CD”, and “built into a daily programme”. “It should be part of your life”. It was suggested that it could also be used at family meetings. Possibly an **app** can be developed of the Guided Imagery to assist patients with advanced disease to re-experience their intrinsic dignity whenever they wish. With repeated practice, conviction of one’s intrinsic worth can become a lived experience.

It was observed that themes varied amongst the different cultures, different illness and along different disease trajectories. Thus a **larger study** can be done to understand the dignity experience taking these variables into account. A **larger quantitative study** can be conducted to elucidate the impact of Dignity Therapy and Guided Imagery. Possibly the lasting impact of Dignity Therapy and Guided Imagery on dignity experience can be evaluated, with the Guided Imagery repeated at regular intervals versus once off.

A study can be done to explore the benefits of Dignity Therapy and Guided Imagery on **family members and healthcare providers**.

Having an overburdened public healthcare system necessitates the rollout of programmes to **support healthcare providers**, for if healthcare providers are supported they will offer better compassionate care.

7. References

- (1) Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: the World Health Organization's global perspective. *J Pain Symptom Manage* 2002;24(2):91-96.
- (2) Robert G. Twycross. *Introducing palliative care*. : Radcliffe Publishing; 2003.
- (3) Breitbart W, Rosenfeld BD, Passik SD. *Interest in Physician-Assisted Suicide*. 1996.
- (4) Field MJ, Cassel CK. *Approaching death: improving care at the end of life*. 2010.
- (5) Meier DE, Emmons C, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998;338(17):1193-1201.
- (6) Sulmasy DP. A biopsychosocial-spiritual model for the care of patients at the end of life. *Gerontologist* 2002;42(suppl 3):24-33.
- (7) Saunders C. The evolution of palliative care. *J R Soc Med* 2001 Sep;94(9):430-432.
- (8) Chochinov HM. Dying, Dignity, and New Horizons in Palliative End-of-Life Care¹. *CA: a cancer journal for clinicians* 2006;56(2):84-103.
- (9) Holland JC. *Psycho-oncology*. : Oxford University Press; 2010.
- (10) Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med* 2002;54(3):433-443.
- (11) Chochinov HM, Cann BJ. Interventions to enhance the spiritual aspects of dying. *J Palliat Med* 2005;8(supplement 1):s-103-s-115.
- (12) LeMay K, Wilson KG. Treatment of existential distress in life threatening illness: a review of manualized interventions. *Clin Psychol Rev* 2008;28(3):472-493.
- (13) Abiven M. Dying with dignity. *World Health Forum* 1991;12(4):375-81; discussion 382-98.
- (14) Madan TN. Dying with dignity. *Soc Sci Med* 1992;35(4):425-432.
- (15) Gove PB. *Webster's third new international dictionary of the English language, unabridged*. : Merriam-Webster; 1981.
- (16) Kant I, Ellington JW. *Ethical philosophy: the complete texts of Grounding for the metaphysics of morals, and Metaphysical principles of virtue, part II of The metaphysics of morals, with On a supposed right to lie because of philanthropic concerns*. : Hackett Publishing; 1994.
- (17) Assembly UG. *Universal declaration of human rights*. UN General Assembly 1948.
- (18) Jacobson N. Dignity and health: a review. *Soc Sci Med* 2007;64(2):292-302.

- (19) Brennan F. Dignity: A unifying concept for Palliative Care and human rights. *Progress in Palliative Care* 2014;22(2):88-96.
- (20) Sulmasy DP. *The varieties of human dignity: a logical and conceptual analysis* 2013.
- (21) Chochinov HM. Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *JAMA* 2002;287(17):2253-2260.
- (22) Proulx K, Jacelon C. Dying with dignity: the good patient versus the good death. *Am J Hosp Palliat Care* 2004 Mar-Apr;21(2):116-120.
- (23) Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Understanding the will to live in patients nearing death. *Psychosomatics* 2005;46(1):7-10.
- (24) Chochinov H. Desire for Death in the Terminally Ill(1995) 152. *Am J Psychiatry* ;1185.
- (25) Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. *The Lancet* 1999;354(9181):816-819.
- (26) Back AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington State: patient requests and physician responses. *JAMA* 1996;275(12):919-925.
- (27) Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon death with dignity act. *N Engl J Med* 2000;342(8):557-563.
- (28) Sullivan AD, Hedberg K, Fleming DW. Legalized physician-assisted suicide in Oregon—the second year. *N Engl J Med* 2000;342(8):598-604.
- (29) De Lima L, Woodruff R, Pettus K, Downing J, Buitrago R, Munyoro E, et al. International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide. *J Palliat Med* 2017.
- (30) Lohman D, Schleifer R, Amon JJ. Access to pain treatment as a human right. *BMC medicine* 2010;8(1):1.
- (31) Radbruch L, Payne S, De Lima L, Lohmann D. The Lisbon Challenge: acknowledging palliative care as a human right. *J Palliat Med* 2013;16(3):301-304.
- (32) Krakauer EL, Wenk R, Buitrago R, Jenkins P, Scholten W. Opioid inaccessibility and its human consequences: reports from the field. *Journal of pain & palliative care pharmacotherapy* 2010;24(3):239-243.
- (33) Abel J, Bowra J, Walter T, Howarth G. Compassionate community networks: supporting home dying. *BMJ Support Palliat Care* 2011 Sep;1(2):129-133.
- (34) Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. *QJM* 2013 Dec;106(12):1071-1075.

- (35) Wegleitner K, Heimerl K, Kellehear A. Compassionate communities: case studies from Britain and Europe. : Routledge; 2015.
- (36) Edelstein L. The Hippocratic oath, text, translation and interpretation. 1943.
- (37) Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol* 2005 Aug 20;23(24):5520-5525.
- (38) Chochinov HM. Dignity and the essence of medicine: the A, B, C and D of dignity-conserving care. : University of North Dakota, Division of Biomedical Communications; 2007.
- (39) Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity in the terminally ill: a cross-sectional, cohort study. *The Lancet* 2002;360(9350):2026-2030.
- (40) Chochinov HM. Dignity and the eye of the beholder. *J Clin Oncol* 2004 Apr 1;22(7):1336-1340.
- (41) McPherson CJ, Wilson KG, Murray MA. Feeling like a burden: exploring the perspectives of patients at the end of life. *Soc Sci Med* 2007;64(2):417-427.
- (42) Wilson KG, Curran D, McPherson CJ. A burden to others: a common source of distress for the terminally ill. *Cognitive behaviour therapy* 2005;34(2):115-123.
- (43) Chochinov HM, Kristjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Burden to others and the terminally ill. *J Pain Symptom Manage* 2007;34(5):463-471.
- (44) Enes SP. An exploration of dignity in palliative care. *Palliat Med* 2003 Apr;17(3):263-269.
- (45) Chochinov HM, Kristjanson LJ, Hack TF, Hassard T, McCLEMENT S, Harlos M. Dignity in the terminally ill: revisited. *J Palliat Med* 2006;9(3):666-672.
- (46) Mount B. Whole person care: beyond psychosocial and physical needs. *Am J Hosp Palliat Care* 1993 Jan-Feb;10(1):28-37.
- (47) Safran DG. Defining the future of primary care: what can we learn from patients? *Ann Intern Med* 2003;138(3):248-255.
- (48) MURILLO M, HOLLAND JC. Clinical practice guidelines for the management of psychosocial distress at the end of life. *Palliative & supportive care* 2004;2(01):65-77.
- (49) McPherson CJ, Wilson KG, Murray MA. Feeling like a burden: exploring the perspectives of patients at the end of life. *Soc Sci Med* 2007;64(2):417-427.
- (50) Peabody FW. The care of the patient. *JAMA* 2015;313(18):1868-1868.
- (51) Portenoy RK, Coyle N, Kash KM, Brescia F, Scanlon C, O'Hare D, et al. Determinants of the Wifflingness to Endorse Assisted Suicide: A Survey of Physicians, Nurses, and Social Workers. *Psychosomatics* 1997;38(3):277-287.

- (52) Sulmasy DP. Death and human dignity. *The Linacre Quarterly* 1994;61(4):7.
- (53) Field MJ, Cassel CK. Approaching death: improving care at the end of life. 2010.
- (54) Chen L, Evans T, Anand S, Boufford JI, Brown H, Chowdhury M, et al. Human resources for health: overcoming the crisis. *The Lancet* 2004;364(9449):1984-1990.
- (55) Cullinan K. Health services in South Africa: A basic introduction. *Health-e News Service* 2006.
- (56) Turner K, Chye R, Aggarwal G, Philip J, Skeels A, Lickiss JN. Dignity in dying: a preliminary study of patients in the last three days of life. *J Palliat Care* 1996 Summer;12(2):7-13.
- (57) Gamlin R. Dignity and palliative care. *Int J Palliat Nurs* 2002;8(1):49-49.
- (58) Pokorny ME. The effect of nursing care on human dignity in the critically ill adult 1989.
- (59) Söderberg A, Gilje F, Norberg A. Dignity in situations of ethical difficulty in intensive care. *Intensive and Critical Care Nursing* 1997;13(3):135-144.
- (60) Street AF, Kissane DW. Constructions of dignity in end-of-life care. *J Palliat Care* 2001;17(2):93.
- (61) Leget C. Analyzing dignity: a perspective from the ethics of care. *Medicine, Health Care and Philosophy* 2013;16(4):945-952.
- (62) Guo Q, Jacelon CS. An integrative review of dignity in end-of-life care. *Palliat Med* 2014;28(7):931-940.
- (63) Rodríguez-Prat A, Monforte-Royo C, Porta-Sales J, Escribano X, Balaguer A. Patient perspectives of dignity, autonomy and control at the end of life: systematic review and meta-ethnography. *PloS one* 2016;11(3):e0151435.
- (64) Hack TF, Chochinov HM, Hassard T, Kristjanson LJ, McClement S, Harlos M. Defining dignity in terminally ill cancer patients: A factor-analytic approach. *Psycho-Oncology* 2004;13(10):700-708.
- (65) Chochinov HM. Dignity therapy: Final words for final days. : OUP USA; 2012.
- (66) McClement S, Chochinov HM, Hack T, Hassard T, Kristjanson LJ, Harlos M. Dignity therapy: family member perspectives. *J Palliat Med* 2007;10(5):1076-1082.
- (67) Chochinov HM, Kristjanson LJ, Breitbart W, McClement S, Hack TF, Hassard T, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *The lancet oncology* 2011;12(8):753-762.

- (68) Houmann LJ, Rydahl-Hansen S, Chochinov HM, Kristjanson LJ, Groenvold M. Testing the feasibility of the Dignity Therapy interview: adaptation for the Danish culture. *BMC Palliat Care* 2010 Sep 22;9:21-684X-9-21.
- (69) PASSIK SD, KIRSH KL, LEIBEE S, KAPLAN LS, LOVE C, NAPIER E, et al. A feasibility study of dignity psychotherapy delivered via telemedicine. *Palliative & supportive care* 2004;2(02):149-155.
- (70) Gagnon P, Chochinov H, Cochrane J, Moreau J, Moignan L, Fontaine R, et al. Dignity therapy: an intervention to diminish psychological distress in palliative care patients. *Psycho-Oncologie* 2010;4(3):169-175.
- (71) Akechi T, Akazawa T, Komori Y, Morita T, Otani H, Shinjo T, et al. Dignity therapy: Preliminary cross-cultural findings regarding implementation among Japanese advanced cancer patients. *Palliat Med* 2012 Jul;26(5):768-769.
- (72) Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y. Good death in cancer care: a nationwide quantitative study. *Ann Oncol* 2007 Jun;18(6):1090-1097.
- (73) Vos MS, De Haes J. Denial in cancer patients, an explorative review. *Psycho-Oncology* 2007;16(1):12-25.
- (74) Nilchaikovit T, Hill JM, Holland JC. The effects of culture on illness behavior and medical care: Asian and American differences. *Gen Hosp Psychiatry* 1993;15(1):41-50.
- (75) Davis A, Konishi E, Mitoh T. The telling and knowing of dying: philosophical bases for hospice care in Japan. *Int Nurs Rev* 2002;49(4):226-233.
- (76) Ando M, Morita T, Akechi T, Okamoto T, Japanese Task Force for Spiritual Care. Efficacy of short-term life-review interviews on the spiritual well-being of terminally ill cancer patients. *J Pain Symptom Manage* 2010;39(6):993-1002.
- (77) Juliao M, Oliveira F, Nunes B, Vaz Carneiro A, Barbosa A. Efficacy of dignity therapy on depression and anxiety in portuguese terminally ill patients: A phase II randomized controlled trial. *J Palliat Med* 2014;17(6):688-695.
- (78) Vergo MT, Nimeiri H, Mulcahy M, Benson A, Emmanuel L. A feasibility study of dignity therapy in patients with stage IV colorectal cancer actively receiving second-line chemotherapy. *J Community Support Oncol* 2014 Dec;12(12):446-453.
- (79) Johnston B, Lawton S, McCaw C, Law E, Murray J, Gibb J, et al. Living well with dementia: enhancing dignity and quality of life, using a novel intervention, Dignity Therapy. *International journal of older people nursing* 2016;11(2):107-120.
- (80) Johnston B, Lawton S, Pringle J. 'This is my story, how I remember it': In-depth analysis of Dignity Therapy documents from a study of Dignity Therapy for people with early stage dementia. *Dementia (London)* 2015 Sep 15.

- (81) Fitchett G, Emanuel L, Handzo G, Boyken L, Wilkie DJ. Care of the human spirit and the role of dignity therapy: a systematic review of dignity therapy research. *BMC palliative care* 2015;14(1):8.
- (82) Chochinov HM, Hack T, Hassard T, Kristjanson LJ. Dignity and psychotherapeutic considerations in end-of-life care. *J Palliat Care* 2004;20(3):134-142.
- (83) Kearney M, Mount B. Spiritual care of the dying patient. *Handbook of psychiatry in palliative medicine* 2000:357-373.
- (84) Breitbart W. Spirituality and meaning in supportive care: spirituality-and meaning-centered group psychotherapy interventions in advanced cancer. *Supportive care in cancer* 2002;10(4):272-280.
- (85) Rousseau P. Spirituality and the dying patient. *J Clin Oncol* 2000 May;18(9):2000-2002.
- (86) Clarke DM, Kissane DW. Demoralization: its phenomenology and importance. *Aust N Z J Psychiatry* 2002;36(6):733-742.
- (87) Kissane DW, Clarke DM, Street AF. Demoralization syndrome--a relevant psychiatric diagnosis for palliative care. *J Palliat Care* 2001;17(1):12.
- (88) Chandler E. Spirituality. *Hosp J* 1999;14(3-4):63-74.
- (89) Robinson A. A personal exploration of the power of poetry in palliative care, loss and bereavement. *Int J Palliat Nurs* 2004;10(1):32-39.
- (90) Cole B, Pargament K. Re-creating your life: a spiritual/psychotherapeutic intervention for people diagnosed with cancer. *Psycho-Oncology* 1999;8(5):395-407.
- (91) Miller DK, Chibnall JT, Videen SD, Duckro PN. Supportive-affective group experience for persons with life-threatening illness: reducing spiritual, psychological, and death-related distress in dying patients. *J Palliat Med* 2005;8(2):333-343.
- (92) Breitbart W, Rosenfeld B, Gibson C, Pessin H, Poppito S, Nelson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psycho-Oncology* 2010;19(1):21-28.
- (93) Breitbart W, Heller KS. Reframing hope: Meaning-centered care for patients near the end of life. *J Palliat Med* 2003;6(6):979-988.
- (94) Metz T. African conceptions of human dignity: Vitality and community as the ground of human rights. *Human Rights Review* 2012;13(1):19-37.
- (95) Nussbaum B. Ubuntu: Reflections of a South African on our common humanity. *Reflections* 2003;4(4):21-26.
- (96) Mabovula NN. The erosion of African communal values: a reappraisal of the African Ubuntu philosophy. *Inkanyiso: Journal of Humanities and Social Sciences* 2011;3(1):38-47.

- (97) Maslow AH. A theory of human motivation. *Psychol Rev* 1943;50(4):370.
- (98) Postle D. Putting the heart back into learning. *Using experience for learning* 1993:33-45.
- (99) Kolcaba K, Fox C. The effects of guided imagery on comfort of women with early stage breast cancer undergoing radiation therapy. *Oncol Nurs Forum* 1999 Jan-Feb;26(1):67-72.
- (100) Baider L, Uziely B, De-Nour AK. Progressive muscle relaxation and guided imagery in cancer patients. *Gen Hosp Psychiatry* 1994;16(5):340-347.
- (101) Walker LG, Walker MB, Ogston K, Heys SD, Ah-See AK, Miller ID, et al. Psychological, clinical and pathological effects of relaxation training and guided imagery during primary chemotherapy. *Br J Cancer* 1999 Apr;80(1-2):262-268.
- (102) Tusek D, Church JM, Fazio VW. Guided imagery as a coping strategy for perioperative patients. *AORN J* 1997;66(4):644-649.
- (103) Lyles JN, Burish TG, Krozely MG, Oldham RK. Efficacy of relaxation training and guided imagery in reducing the aversiveness of cancer chemotherapy. *J Consult Clin Psychol* 1982;50(4):509.
- (104) Eremin O, Walker MB, Simpson E, Heys SD, Ah-See AK, Hutcheon AW, et al. Immunomodulatory effects of relaxation training and guided imagery in women with locally advanced breast cancer undergoing multimodality therapy: a randomised controlled trial. *The Breast* 2009;18(1):17-25.
- (105) Renz M, Mao MS, Omlin A, Bueche D, Cerny T, Strasser F. Spiritual experiences of transcendence in patients with advanced cancer. *Am J Hosp Palliat Care* 2015 Mar;32(2):178-188.

Appendix 1

MMSE - Mini Mental Status Examination

ORIENTATION

What is the? Year? Season? Date? Day? Month? /5

Where are we? Country? State? Suburb? Street? Room? /5

REGISTRATION (1 point for each correct reply on the first attempt) /3

I am going to name 3 words. After I have said all 3, I want you to repeat them.

(DOG CAR FAN)

Remember what they are because I am going to ask you to name them again in a few minutes.

Name the 3 words several more times (maximum 5 times) if needed, for the patient to report correctly. (Record number of trials_____)

ATTENTION AND CALCULATION /5

Spell WORLD backwards (D L R O W)

or Serial sevens. Ask the patient to count backwards by 7 from 100 (100,93,86,79,72,65)

Stop after five answers (1 point for each correct answer) Use higher of the 2 scores.

RECALL

Do you recall the three words I asked you to remember?

(Give 1 point for each correct answer) /3

LANGUAGE

What is this called? (Show **WATCH** then **PENCIL**) /2

I'd like you to repeat a phrase after me: "**No ifs, ands, or buts.**" /1

PAPERWORK

1. Have the patient read and do the following "Close your eyes" /1

2. Write any complete sentence (subject, object, verb). /1

3. Copy this design (intersecting pentagons) /1

4. Give patient paper, ask them to take into their R/L hand, fold the paper in half once with both hands, and put the paper down on the floor. /3

MMSE SCORE ____/30

Appendix 2

PATIENT DEMOGRAPHIC REPORT

1. Study Number: _____
2. Study Entry Date: (DD/MM/YY): ____/____/____
3. Age: _____
4. Sex: _____

5. Marital Status (check one):

- | | | |
|------------------|-----------------------|---------------------------|
| 1. Never Married | 3. Divorced/Separated | 5. Common law/ Cohabiting |
| 2. Married | 4. Widow(er) | |

6. Primary Social Support (check those that apply):

- | | | |
|-------------------|----------------------|----------|
| 1. Spouse/Partner | 4. Child(ren) | 7. None |
| 2. Parent(s) | 5. Other relative(s) | 8. Other |
| 3. Sibling(s) | 6. Friend(s) | |

7. Usual Residence:

- | | |
|-----------------------------|----------------|
| 1. Urban/Metropolitan _____ | 2. Rural _____ |
|-----------------------------|----------------|

8. Race:

- | | | |
|--------------|-------------|----------|
| 1. Caucasian | 3. Coloured | 5. Other |
| 2. Black | 4. Indian | |

9. Do you consider yourself to be a religious/spiritual person?

- | | | |
|----------------|--------------|--------------------|
| 1. Not at all. | 2. Somewhat. | 3. Yes, very much. |
|----------------|--------------|--------------------|

10. What is your Religion?

- | | | |
|--------------|----------------|---------|
| 1. Christian | 3. Muslim | 5. None |
| 2. Hindu | 4. Other _____ | |

11. Education Level Completed:

- | | | |
|------------------------|---------------------|-----------------|
| 1. No Formal Education | 3. Secondary School | 4. Tertiary |
| 2. Primary School | | 5. Postgraduate |

12. Present Occupation:

- | | | |
|---------------|---------------|---------------------------|
| 1. Unemployed | 3. Home maker | 5. Skilled /Manager |
| 2. Retired | 4. Unskilled | 6. Professional/Executive |

13. Do you know the diagnosis/illness you have? (Primary Cancer Site/ Metastasis OR Non-cancer Terminal Diagnosis):

14. Length since initial diagnosis: _____ years

15. At the present time, do you have or are you being treated for any other major medical condition?

Thank you for completing this questionnaire.

Appendix 3

Semi-Structured Interview Guide:

- (1) In terms of your own illness experience, how do you define the term dignity?
- (2) What supports your sense of dignity?
- (3) What undermines your sense of dignity?
- (4) Are there specific experiences you can recall in which your dignity was compromised?
- (5) Are there specific experiences you can recall in which your dignity was supported?
- (6) What would have to happen in your life for you to feel that you no longer had a sense of dignity?
- (7) Some people feel that life without dignity is a life no longer worth living. How do you feel about that?
- (8) Do you believe that dignity is something you hold within you, and/or is it something that can be given or taken away by others?

Appendix 4

Patient Feedback Questionnaire.

We would appreciate your feedback and impressions of the interventions you received. Please help us answer the following questions:

1. I have found the Intervention to be helpful to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

2. I have found the Intervention to be satisfactory.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

3. The Intervention made me feel that my life currently is more meaningful.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

4. The Intervention has given me a heightened sense of purpose.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

5. The Intervention has given me a heightened sense of dignity.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

6. The Intervention has lessened my sense of suffering.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

7. The Intervention has lessened my feelings of anxiety and depression.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

8. The Intervention has increased my will to live.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

9. I believe the Intervention has or will be of help to my family.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

10. I believe my participation in the Intervention could change the way my family sees or appreciates me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

11. I believe my participation in the Intervention could change the way my health care providers see or appreciate me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
-------------------	----------	----------------------------	-------	----------------

What are your reasons for that opinion?

Any other comments regarding your experience of Dignity Therapy and Guided Imagery Protocol, and how you think it might be improved, would be most appreciated.

Thank you for completing this questionnaire.

Appendix 5

Information Sheet for: Understanding the Dignity Experience and Exploring the Impact of Dignity Therapy and Guided Imagery on Patients with Serious Illness - from a South African Perspective

Thank you for giving your time to hear about this research study. My name is Dr Balbadhur, and I am doing the above study for a Masters degree in Palliative Medicine.

This information sheet tells you about a study that you may wish to take part in. You may have some further questions to help you decide whether you want to take part. You can ask any further questions from your clinical team, from the researcher, or using the telephone numbers at the end. This information sheet is for you to keep.

Thank you for thinking about whether you want to take part. Please take your time to make a decision.

What is the purpose of the study?

We wish to investigate the dignity experience of patients with serious illness and investigate the impact of dignity enhancing interventions on up to 12 patients with serious illness

Do I have to take part?

No, you don't have to take part. If you do agree to take part, you are free to withdraw from the interview at any time without giving us any reason. Whether or not you take part, your care will NOT be affected in ANY WAY. If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part, and you may want to talk it over with your family, friends or someone in your care team.

What will happen if I take part?

The researcher will speak to you and interview you about your experience of your illness, and this will include your experience of self-worth in illness. This will be audio-recorded. It will take around 30 minutes for the first interview. Then at another visit a few days later as per your convenience, you will participate in a dignity enhancing intervention which will last about 30 minutes where you will be able to reflect on your life's accomplishments. The researcher will meet you one more time a few days later to give you a legacy document based on your conversation to give to your family if you wish as a memory of your accomplishments. Thereafter within a few days, as per your convenience again, we will meet with you to give you your legacy document and share a guided imagery on dignity with you. Thereafter we will interview you on the impact of these interventions on your state of wellbeing and get your feedback on the dignity intervention for another 30 minutes.

Benefits of the study?

There may be benefit for participants of the study as previous studies have shown beneficial impacts on the dignity of patients who experienced dignity therapy. If this study shows beneficial impact on a patient's experience of dignity in serious illness, it will be suggested that dignity interventions become a routine care of patients with serious illness.

What are the risks of the study?

There are few study risks. Answering some questions might cause an emotional response. If this happens, you may ask to stop the study or the researcher will stop the study and ask you if you would like assistance. It is possible that talking about your experiences may bring up emotions and feelings that you may wish to discuss further. The researcher will be available to discuss this with you, and should you wish, can refer you to an appropriate professional, either the hospice social worker or a clinical psychologist.

Will my taking part in this study be kept confidential?

All the information which we collect during the interview will be kept strictly confidential. You will not be identified in any way, and your personal details (for example name and address) will be kept separately from the information you give. We will use a number and not your name on any information you give us. This will be kept under lock and key in the researcher's office. No-one outside the study will have access to the information you give us. That information will be treated as confidentially as all the other information you give us, and no-one outside this study will be able to find out your name or any other information that would identify you. All research data will be kept for 6 years without publication or 2 years after publication and destroyed thereafter.

How will I know about the results of the study?

At the end of the study a report will be sent to the hospice and to the people who took part in the study. The researcher will also invite you to hospice to verbally inform you of the findings of the research and will send a summary of the research findings to you.

Who is organising the research?

If you need to talk to anyone about this research, you can contact the following people. The study is funded by the researcher herself as part of her Masters in Palliative Medicine.

If you have any questions about the study:

Researcher: Dr Raksha Balbadhur, Tel 032-5336728

Study supervisor: Dr Liz Gwyther, Tel 021-4066707

If you have any questions about your human rights of any ethical issues about the study:

UCT Human Research Ethics Committee:

Mrs Lamees Emjedi

Human Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338

HPCA Human Research Ethics Committee

Mrs Cheryl Borresen

E-mail: cborresen@iburst.co.za

Telephone: 031 261 7868

Appendix 6

Consent form for: Understanding the Dignity Experience and Exploring the Impact of Dignity Therapy and Guided Imagery on Patients with Serious Illness - from a South African Perspective

1. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my care being affected.
3. I agree to take part in the above study.

Name _____

Signature _____

Date _____

Researcher: Signature _____

Date: _____

Witness: Name

(from clinical team or family member)

Signature _____ Date: _____

Appendix 6

Consent form for Audiotaping: Understanding the Dignity Experience and Exploring the Impact of Dignity Therapy and Guided Imagery on Patients with Serious Illness - from a South African Perspective

1. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my care being affected.
3. I agree to the interview being audiotaped.

Name _____

Signature _____

Date _____

Researcher: Signature _____

Date: _____

Witness: Name

(from clinical team or family member)

Signature _____ Date: _____

Appendix 7

Dignity Therapy Question Protocol and Guided Imagery

Dignity Psychotherapy Question Protocol

1. Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
2. Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
3. What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc.)? Why were they so important to you, and what do you think you accomplished in those roles?
4. What are your most important accomplishments, and what do you feel most proud of?
5. Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
6. What are your hopes and dreams for your loved ones?
7. What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, spouse, parents, siblings, extended family members)?
8. Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
9. In creating this permanent record, are there other things that you would like included?

Guided Imagery:

As I sit here, I relax my body completely...if there is any tension I am holding in any muscles of this body, I relax them...from my toes...I invite the tiny, tiny muscles of my toes to become fully relaxed...and I thank my feet for carrying me on this full journey through this life.... I relax the muscles of my calves...my legs... my buttocks...my back...my spine...my stomach...I take a deep breath in...filling my lungs with peace...and I breathe out...I let go of all the stale air in my lungs.... I do this again.... I breathe in peace and I breathe out...and I allow my breath to find its own rhythm. I relax the muscles of my arms...my fingers...my neck and shoulders...we can hold so much tension here...and I just let them go...I relax them even further...I relax the muscles of my scalp...my face... In this moment... I don't need to pretend...to hold only onto any masks of roles and responsibilities.... I can just be myself...! And in this moment... after reflecting on my unique life's journey... all that matters is the bliss and contentment...that I feel in just being me in this moment.... With my mind... I visualize the radiant living energy that I am... that has journeyed through life...the living being that I truly am, filling this body with light and life.... I am the untouchable living spirit...and no illness or disability..., no one... and nothing... not even serious illness... can touch this...! I am peace... I am love... I am bliss... I am worthy of esteem and respect...I am free! I am immortal...I am eternal...I am...This is my imperishable intrinsic dignity...! My innate inherent worth...! Not affected by people or situations or circumstances... but this is Who I really am, always eternally! And within this lies my real self-worth! My dignity!

Appendix 8

Ms. R Sookdeo
Manager
Verulam Regional Hospice Association
45 Assafa Way
Riyadh
Verulam
4340

5 October 2015

Dear Ms. R Sookdeo,

Research: Understanding the Dignity Experience and Exploring the Impact of Dignity Therapy and Guided Imagery on Patients with Terminal Illness - from a South African Perspective

I am writing to request your permission for Verulam Regional Hospice to be a study site for my research, which is self-funded and part of my Masters in Palliative Medicine at the University of Cape Town.

Palliative care is the care of patients with advanced disease, for whom the focus of care is the relief and prevention of suffering and the quality of life. The area of suffering that we are focusing on in this study is the experience of dignity in patients with terminal illness. Dignity in living and dying is a basic tenant of palliative care but as yet, there are no studies to help us understand the dignity experience in South African patients with terminal illness.

The study is a qualitative study that aims to understand the experience of dignity amongst patients with terminal illness. We also aim to explore the impact of Dignity Therapy and Guided Imagery on the dignity experience of patients with terminal illness. This dignity intervention will be conducted and its impact explored qualitatively in improving the dignity of patients with terminal illness. This study is based on the work done in this field by the credible and world renowned Professor Chochinov and his team (Dignity in Care) in Canada. The dignity therapy intervention has shown to be beneficial for patients with terminal illness in Canada, Australia, UK, Portugal, Texas and Denmark.

If you agree, I will introduce the research study to your staff. I, as a master's student in palliative medicine, will be conducting all the research and Dr Liz Gwyther is my supervisor. This study will not begin until we have full ethical approval.

I am writing to outline some basic study information:

- *Who are we recruiting?*

We are recruiting a total of 12 participants, from two hospices giving us a range of adult participants with terminal illness from diverse age, gender, socio-economic and cultural/racial populations.

- *How will patients be approached to ask them if they want to take part?*

We ask that your staff identify patients who meet the criteria, and then refer them to me. I will meet the potential participants and explain that we are recruiting patients to assess the dignity experience of patients with advanced illness and we will conduct dignity enhancing interventions with them. The study will involve 3 to 4 meetings of 30-minute duration. I will give full information and an information sheet and invite them to take part. If they agree to take part, the researcher will ask for informed consent.

- *How will data collection happen?*

I will then conduct the interviews. I will store the data in a locked cabinet in my office and will keep the personal information (e.g. name) separate from the questionnaire data on my computer which is password protected. The patient's name will not appear on the interviews/questionnaire which will only have a study number as an identifier.

- *What if a patient becomes distressed?*

The study has a distress protocol (see attached). All patients will have the opportunity to halt the interview at any time, and will have debriefing (i.e. time to talk without data being collected) at the end of the interview. If I am concerned about level of respondent distress, I will refer the respondent to an appropriate counsellor and I am writing to ask if your counselling staff would be prepared to take on this role.

- *What are the responsibilities of the study site?*

1. I am asking hospice staff to assist in identifying patients who meet the study criteria and to refer them to me.

2. I am also asking that should a patient become distressed during the interview that your counselling staff would be prepared to provide the necessary support for the participant. We have found in previous studies that participants welcome the opportunity to respond to questions asked in the Dignity Therapy Question Protocol and that distress is infrequent.

Please would you note your agreement to provide this support of recruiting, selection and counselling when you respond to my request to conduct research within your facility.

- *What about study feedback?*

I will present the results of the study to the hospice staff and participants who wish to hear about the study results once it is complete. I will also provide a brief summary that can be disseminated on the findings for display within your service.

We look forward to working with you and fixing the date for launch once we have full ethical approval, and translated materials.

Please don't hesitate to contact me should you require further information in the meantime. I encourage you to raise any thoughts with me. You may raise any ethical concerns with the UCT Research Ethics Committee contact and the HPCA Research Ethics Committee contact.

Yours sincerely,

Dr Raksha Balbadhur
Raksha56@gmail.com
Tel 032-5336728

Supervisor - Dr Liz Gwyther, Tel 0214066707

UCT Research Ethics Committee:

Mrs. Lamees Emjedi
Research Ethics Committee
E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory
Telephone: 021 406 6338

HPCA Human Research Ethics Committee

Mrs Cheryl Borresen
E-mail: cborresen@iburst.co.za
Telephone: 031 261 7868 / Cell 082 797 1023

Appendix 8

The Manager
Dolphin Coast Hospice
26 Berthwell Dr
KwaDukuza
4449

18 July 2016

Dear Sir/Madam,

Research: Understanding the Dignity Experience and Exploring the Impact of Dignity Therapy and Guided Imagery on Patients with Terminal Illness - from a South African Perspective

I am writing to request your permission for Dolphin Coast Hospice to be a study site for my research, which is self-funded and part of my Masters in Palliative Medicine at the University of Cape Town.

Palliative care is the care of patients with advanced disease, for whom the focus of care is the relief and prevention of suffering and the quality of life. The area of suffering that we are focusing on in this study is the experience of dignity in patients with terminal illness. Dignity in living and dying is a basic tenant of palliative care but as yet, there are no studies to help us understand the dignity experience in South African patients with terminal illness.

The study is a qualitative study that aims to understand the experience of dignity amongst patients with terminal illness. We also aim to explore the impact of Dignity Therapy and Guided Imagery on the dignity experience of patients with terminal illness. This dignity intervention will be conducted and its impact explored qualitatively in improving the dignity of patients with terminal illness. This study is based on the work done in this field by the credible and world renowned Professor Chochinov and his team (Dignity in Care) in Canada. The dignity therapy intervention has shown to be beneficial for patients with terminal illness in Canada, Australia, UK, Portugal, Texas and Denmark.

If you agree, I will introduce the research study to your staff. I, as a master's student in palliative medicine, will be conducting all the research and Dr Liz Gwyther is my supervisor. This study will not begin until we have full ethical approval.

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We ask that your staff identify patients who meet the criteria, and then refer them to me. I will meet the potential participants and explain that we are recruiting patients to assess the dignity experience of patients with advanced illness and we will conduct dignity enhancing interventions with them. The study will involve 3 to 4 meetings of 30-minute duration. I will give full information and an information sheet and invite them to take part. If they agree to take part, the researcher will ask for informed consent.

- *How will data collection happen?*

I will then conduct the interviews. I will store the data in a locked cabinet in my office and will keep the personal information (e.g. name) separate from the questionnaire data on my computer which is password protected. The patient's name will not appear on the interviews/questionnaire which will only have a study number as an identifier.

- *What if a patient becomes distressed?*

The study has a distress protocol (see attached). All patients will have the opportunity to halt the interview at any time, and will have debriefing (i.e. time to talk without data being collected) at the end of the interview. If I am concerned about level of respondent distress, I will refer the respondent to an

appropriate counsellor and I am writing to ask if your counselling staff would be prepared to take on this role.

- *What are the responsibilities of the study site?*

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Please would you note your agreement to provide this support of recruiting, selection and counselling when you respond to my request to conduct research within your facility.

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I will present the results of the study to the hospice staff and participants who wish to hear about the study results once it is complete. I will also provide a brief summary that can be disseminated on the findings for display within your service.

We look forward to working with you and fixing the date for launch once we have full ethical approval, and translated materials.

Please don't hesitate to contact me should you require further information in the meantime. I encourage you to raise any thoughts with me. You may raise any ethical concerns with the UCT Research Ethics Committee contact and the HPCA Research Ethics Committee contact.

Yours sincerely,

Dr Raksha Balbadhur
Raksha56@gmail.com
Tel 032-5336728

Supervisor - Dr Liz Gwyther, Tel 0214066707

UCT Research Ethics Committee:

Mrs Lamees Emjedi
Research Ethics Committee
E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory
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HPCA Human Research Ethics Committee

Mrs Cheryl Borresen
E-mail: cborresen@iburst.co.za
Telephone: 031 261 7868 / Cell 082 797 1023

Appendix 9

Distress Protocol

All participants were fully informed as to the nature of the issues to be in the interview. Any participant who appears to become distressed during the sessions was asked if they would like to stop the interview or intervention and offered the opportunity to resume the interview/intervention at a time of their convenience or to abandon the interview/intervention at any phase. The interviewer will pass on any information or request to the psychosocial counsellor at the patient's request. All information is treated as confidential except in the situation of the patient's safety being at risk, in which case the information may be acted upon. The participant will be referred to the hospice team for symptom management if necessary or psychosocial support; in addition, a clinical psychologist is available to counsel the participant if s/he becomes emotionally distressed.

Isithasiselo 3

Ingxenye yonhlolovo:

- (1) Ngokwakho ukudlula ezimweni zokugula, ungasichaza ngokuthini isithunzi?
- (2) Yini ekusizayo ngokucabanga kwakho ngesithunzi?
- (3) Yini ejivaza ukuqonda kwakho ngesithunzi?
- (4) Kungabe kukhona yini isikhathi ongasikhumbula lapho isithunzi sakho kwafanele usehlise?
- (5) Kungabe kukhona yini isikhathi ongasikhumbula lapho isithunzi sakho sabanokuhlonipheka khona?
- (6) Yini okwamele kwenzeke ukuze uzizwe ukuthi isithunzi sakho silahlekile?
- (7) Abanye abantu banomuzwa wokuthi ukuphila ngaphandle kwesithunzi impilo ayiphileki kahle. Uzizwa kanjani ngalokho?
- (8) Ingabe uyakholelwa yini ukuthi isithunzi yinto oyiphila ngaphakathi kuwe, okanye ingabe into ongayinikwa noma ithathwe kuwe ngabanye abantu?

Isithasiselo 4

Izimpendulo zesiguli

Singakujabulela kakhulu ukuthola uvo lwakho mayelana nempatho oyitholile eHospice, kungabe Izinga Lokunakekela asebegula kakhulu noma abagulela ukufa eHospice kanye nokunenezelwa.

1. Ngaluthola uhlelo lokungenelela luwusizo kakhulu kimina.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

2. Ngaluthola uhlelo lokungenelela lugculisa.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

3. Uhlelo lokungenelela lungenze ngazizwa impilo yami njengamanje ibaluleke kakhulu.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

4. Uhlelo lokungenelela lungiphe injongo enkulu yokuphokophelela/yokulangazelela ukuphila.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

5. Uhlelo lokungenelela lwenze lanyuka izinga lesithunzi sami.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

6. Uhlelo lokungenelela lwehlise iminjunju yezinhlungu.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

7. Uhlelo lokungenelela lwehlise umuzwa wokukhathazeka nowengcindezi.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

8. Uhlelo lokungenelela lukhuphule izinga lokulangazelela ukuphila.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

9. Ngiyakholwa ukuthi uhlelo lokungenelela lube noma luzoba usizo emndenini wami.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

10. Ngiyakholwa ukuthi ukubamba kwami iqhaza kuloluhlelo lokungenelela luzoshintsha indlelaumndeni wami ongibona noma ongithatha/ongiphatha ngayo.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

11. Ngiyakholwa ukuhi ukubamba kwami iqhaza kuloluhlelo lokungenelela luzoshintsha indlela abazempilo abangibona noma abangithatha ngayo.

Ngiyaphika kakhulu	Ngiyaphika	Ngiphakathi nendawo	Ngiyavuma	Ngiyavuma kakhulu
--------------------	------------	---------------------	-----------	-------------------

Kungabe zithini izizathu zakho zalombono?

Singawujabulela kakhulu noma yimuphi omunye umbono onawo mayelana nesipiliyoni sakho sokunakekelwa ezibhedlela noma Dignity Therapy and Guided Imagery Protocol, futhi nokuthi singenza njani ukuthuthukisa izinga.

SIYABONGA KAKHULU NGESIKHATHI SAKHO UPHENDULA LEMIBUZO

Isithasiselo 5

Iphepha Lolwazi Mayelana: Ukuqonda ngesipiliyoni sesithunzi nangokuhlola ngomthelela we Dignity Therapy and Guided Imagery nangohlelo lokungenelela kweziguli esezigulela ukufa – evela eSouth Africa

Siyabonga ngokunikela ngesikhathi sakho ukuzwa mayelana nesifundo sethu. Igama lami ngingu Dr Balbadhur ngenza ucwaningo kwiziqu eziphakeme mayelana ne Palliative Medicine.

Leliphepha lolwazi likutshela mayelana nesifundo ongafisa ukuthatha iqhaza kuso. Ungase ube neminye imibuzo engakusiza ukuthatha isinqumo sokungenelela kulohlelo. Ungabuza noma imiphi eminye imibuzo eqenjini lakho lezempilo, kusukela kumcwaningi, noma usebenzisa izinombolo zocingo ekupheleni.

Siyabonga ukucabanga ukuthi ingabe uyafuna yini ukuba ingxenywe. Sicela uzinike isikhathi sakho ngaphambi kokuthatha isinqumo.

Iyini inhloso yocwaningo?

Sifisa ukuba iphenye isipiliyoni ngesithunzi seziguli ezinezigulo ezibulalayo siphinde siphanye nomthelela wokungenelela emkhankasweni wokubuyiswa kwesithunzi kwaleziguli. Sizocwaninga abantu abangevile kwaba yishumi nambili.

Ingabe kumele ngithathe ingxenywe?

Cha, awuphoqiwe ukuthatha ingxenywe. Uma uvumelana ukuthatha ingxenywe, ukhululekile ukuba uhoxe ekungeneleni inhlobo nganoma isiphi isikhathi ngaphandle kokusinika isizathu. Noma ngabe uyayithatha ingxenywe noma awuyithathi lokho angeke kukubeke engcupheni yokuhlukunyezwa NOMA IKANJANI. Uma ungenela uvumelana nokuthatha okuyingxenywe, uzocelwa ukuba usayine ifomu lemivume, okubonisa ukuthi uyavuma ukwenza kanjalo. Ungathatha isikhathi sokucabanga ukuthi ungathanda yini ukuba yingxenywe noma cha noma ngabe ufuna ukukhuluma nomndenini wakho, abangane noma umuntu ethimbeni lakho ukunakekelwa.

Kuyokwenzekani uma ngibamba iqhaza kulolucwaningo?

Umcwaningi oqeqeshiwe wagoda kwezocwaningo uzokhuluma nawe akubuze ngesipiliyoni sakho ngesigulo sakho esingalapheki efisa ukwazi kabanzi ngezina osudlule kuzo nobuwena ngalesisifo. Ingxoxo yethu izoqoshwa kwisiqupho mazwi. Ingxoxo izothatha imizuzu engama 30. Uzoba yingxenywe yeqembu elizocwaningwa bese futhi umcwaningi ephinde ngokuhamba kwesikhathi azokhuluma nawe uwedwa ngesikhathi enizovumelana ngaso, nalapho futhi imizuzu ngeke yeve kweyama 30 nalapho ozobe ulandisa khona umcwaningi ngezigameko osuke wahlangana nazo. Ekupheleni kocwaningo umcwaningi uzobe esenza ibhukwana eliqukethe konke ebenikuxoxa elizohlala liyi gugu lesikhumbuzo emndenini wakho ngamagalelo akho lelibhukwana uma ufisa ungalidlulisela emndenini wakho. Umcwaningi uzophinda abuye futhi emva kwezinsukwana ezothola ukuthi kube namphumela muni ukuxoxisana naye.

Izinzuzo ngocwaningo?

Kubukeka kuzoba nenzuzo enkulu ngalolucwaningo ngoba ezikhathini eziphambilini kutholakele ukuthi iziguli ezithola unyango ngesithunzi ziba nokuzethemba okukhulu nokubuyelwa isithunzi. Uma lolucwaningo luvumelana naloku okutholakale ngaphambili kuzobe sekuncomeka ukuthi ukungenelela ekubuyisweni kwesithunzi zeziguli ezinezigulo ezibulalayo kube yinto esemthethweni nengumgomo olandelwayo.

Ziyini izingozi cwaningo?

Zimbalwa izingozi cwaningo. Ukuphendula eminye imibuzo engase ibangele ubuhlungu noma ukuphazamiseka kwenhlizi. Kunabaluleki abaqeqeshiwe ukuthi bakwazi ukukulekelela ngosizo olusezingeni uma imibuzo ikufaka esimweni sokuhlukumezeka emoyeni. Umcwaningi uyolimisa uphenyo abuze ukuthi kungabe udinga usizo lwabaluleki yini. Kungenzeka ukuthi ngesikhathi ulandisa umcwaningi

ngezigameko osudlule kuzo kube nezikhawu zomunyu nemizwa engemihle, umcwaningi uyoza ngawowonke amandla ukukusiza kulokho. Umcwaningi futhi uyokwazi ukukudlulisela kubantu abaqeqeshwe ngokugcwele ukubhekana nosizo oyobe ulidinga ngalesosikhathi okungaba usonhlalakahle noma umeluleki wengqondo nomoya.

Kungabe ukubamba iqhaza kwami kuphephe kangakanani na ngeke yini igama lami lisabalaliswe na?

Lonke ulwazi oluzoqoqwa luzoba yimfihlo. Akekho umuntu ongesiyo ingxenye yocwaningo oyoba nesandla ekutholeni imininingwane yalolucwaningo. Igama lakho ngeke livele ndawo sizosebenzisa izinombolo njengamakhodi ethu Umcwaningi uzogcina lonke ulwazi aluthole kuwe luvalwe e hhovisi lakhe. Akekho noyedwa oyokwazi ukumatanisa ulwazi osinike lona negama lakho. Lonke ulwazi oluqoqwe kulolucwaningo luzogcinwa iminyaka eyisithupha lungakashicilelwa bese lugcinwa iminyaka emibili emva kokushicilelwa bese lushabalaliswa.

Ngizokwazi kanjani mayelana imiphumela yocwaningo?

Maseluqediwe ucwaningo yonke inqikithi yombiko oqoqiwe uzothunyelwa ezikhungweni ezinakekela abantu abanezigulo ezibulalayo nakubantu ababambe iqhaza kulolucwaningo. Umcwaningi uzophinda futhi akubize nizoxoxisana esikhungweni ukukwazisa ngemiphumela yocwaningo aphinde futhi akuthumelele umbiko ofinyeziwe ngakutholile ngocwaningo.

Ngubani ukhlehla ucwaningo?

Lolucwaningo lukhokhelwa uye uqobo umcwaningi akanabo abaxhasi. Uma udinga ukukhuluma nomuntu ngalolu cwaningo, ungaxhumana nabantu abalandelayo.

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Isithasiselo 6

**IFOMU LOKUNIKEZA IMVUME: UKUQONDA KANGCONO ISIPILIYONI SESITHUNZI KANYE
NOKUHLOLA UMTHELELELA WOKULASHWA NGESIZOTHA NGOKOMQONDO
OKULUNGISIWE KWEZIGULI EZIGULELA UKUFA – eSouth Africa**

1. Ngiyaqinisekisa ukuthi ngifundile, ngaliqonda ikhasi lolwazi futhi ngilitholile ithuba lokubuza imibuzo.
2. Ngiyaqonda ukuthi angiphoqiwe futhi ngivumelekile ukuhoxa noma inini ngaphandle kokunikeza isizathu kanye nokuthi unakekelo lwami angeke luthintke ngenxa yokuhoxa kwami.
3. Ngiyavuma ukuba ingxenye yalolucwaningo olungenhla

Igama _____

Sayina _____ Usuku _____

Umcwaningi:

Sayina _____ Usuku _____

Ufakazi: igama

(omunye weqembu elilaphayo okanye ilunga lomndeni)

Sayina _____ Usuku _____

Isithasiselo 6

**IFOMU LOKUNIKEZA IMVUME EQOSHIWE: UKUQONDA KANGCONO ISIPILIYONI
SESITHUNZI KANYE NOKUHLOLA UMTHELELELA WOKULASHWA NGESIZOTHA
NGOKOMQONDO OKULUNGISIWE KWEZIGULI EZIGULELA UKUFA – eSouth Africa**

1. Nginyaqinisekisa ukuthi ngifundile, ngaliqonda ikhasi lolwazi futhi ngilitholile ithuba lokubuza imibuzo.
2. Nginyaqonda ukuthi angiphoqiwe futhi ngivumelekile ukuhoxa noma inini ngaphandle kokunikeza isizathu kanye nokuthi unakekelo lwami angeke luthintke ngenxa yokuhoxa kwami
3. Ngiyavuma ukuthi iqoshwe le nkulumo yethu.

Igama _____

Sayina _____ Usuku _____

Umcwaningi:

Sayina _____ Usuku _____

Ufakazi: igama

(omunye weqembu elilaphayo okanye ilunga lomndeni)

Sayina _____ Usuku _____

Isithasiselo 7

INQUBO YEMIBUZO YOKULASHWA NGESIZOTHA NGOKOMQONDO OKULUNGISIWE

INQUBO YEMIBUZO YOKULASHWA NGESIZOTHA NGOKOMQONDO

Ake uthi fahla kancane ngempilo yakho ikakhulukazi izingxenye ozikhumbulayo noma ocabanga ukuthi zibaluleke kakhulu? Kunini lapho owawuzizwa uphile kakhulu khona?

Zikhona izinto ezithile ongafisa ukuthi umndeni wakho uzazi ngawe? Zikhona izinto ezithile ongafisa bazikhumbule ngawe?

Iliphi iqhaza elibalulekile oke walidlala empilweni (iqhaza emndenini, iqhaza emsebenzini, iqhaza emphakathini nokunye)? Kwakubaluleke ngani kuwena? Yini ocabanga ukuthi yaba impumelelo kulelo qhaza owalibamba?

Yiziphi izinto ophumelele kuzona kakhulu? Ikuphi ozizwa uziqhenya kakhulu ngako?

Zikhona izinto ezithile ocabanga ukuthi kumele zishiwo kwabathandiweyo bakho noma izinto ofisa ukuphinde uzisho futhi?

Yimaphi amaphupho namathemba owafisela abathandiweyo bakho?

Ikuphi okufundile empilweni ongafisa ukukudlulisela kwabanye? Yiziphi izeluleko noma amazwi akhayo ofisa ukuwadlulisela (kwindodana, indodakazi, umyeni, unkosikazi, abazali, nabanye)?

Akhona amazwi noma mhlampe izeluleko ofisa ukuzinikeza umndeni wakho okuzobasiza ukuthi balungisele ikusasa?

Ekwakheni lengqopho engasuleki, zikhona ezinye izinto ofisa ukuthi zifakwe?

Manje akesivale umhlangano wethu ngokuthi siphakamise wena:

Indlela yokukhulula umqondo: njengoba ngihleli la, ngikhulula umzimba wami ngokwanele... uma kukhona ukukhathazeka engikubambe kunoma iziphi izicubu zomzimba, ngithambisa... kusukela ezinzwaneni...ngitshela izicubu ezincane ezisenzinwaneni ukuthi zithambisise... ngibonga izinyawo zami ngokungithwala kulolu hambo lwami empilweni...ngithambisa izicubu zezihluzi zami...zemilenze yami... zezinqe zami... zomhlane wami... zomgogodla wami...zesisu sami... ngidonsa umoya... ngigcwalise amaphaphu ami ngokuthula... bese ngikhipha umoya... ngikhipha wonke umoya ongcolile emaphashini ami... ngiyaphinda ngiyakwenza lokhu bese ngivumela ukuphefumula kwami kuthole isigqi sawo. Ngithambisa izicubu zezingalo zami...zeminwe yami... zomqala wami kanye nezamahlombe ami...kulezi zindawo ezingabamba ukukhathazeka kwethu, ngiyazikhulula... ngiyaphinda ngizithambisa kakhulu... ngithambisa izicubu zekhanda lami...zobuso bami...kulo mzuzu angidingi ukuzenzisa... ukubambelela ezintwela okwakumele ngizenze...ngingaba imina nje. Kulo mzuzu emva kokubuka uhambo lwempilo yami, okubalulekile kusenjabulweni nasekusekuziqhenyeni engikuzwayo ekubeni imina... ngomqondo wami ngibona umfutho okhanyayo onokuphila engiwufaka kulo mzimba kanye nokukhanya nempilo... ngiwumphefumulo ophilayo ongathinteki futhi akukho zifo... akukho muntu... futhi akukho lutho okungawuthinta...ngiwukuthula...ngiwuthando...ngiyinjabulo... ngifanelekile...ngikhululekile... ngingunaphakade angifi...ngiwu...lesi isizotha zami esingeke saphela! Ukubaluleka kwami... okungathelelwa abantu noma izimo... kodwa ilokhu engiyikona njalo kuze kube ingunaphakade!